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Testing experience based co design: Understanding patient and staff experience of experience based co design on an accute mental health ward to promote patient centred service improvement
A multiple methods study

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Testing experience based co design

Understanding patient and staff experience of experience based co design on an acute mental health ward to promote patient centred service improvement: A multiple methods study

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Abstract

Background

There is little evidence on using patient experience to improve psychiatric hospital care. Patient involvement in the design of health care is a key policy initiative but few empirical studies address this.

Aims and objectives

The main aims were to: (1) study the implementation of a service user-led Experience-Based Co design (EBCD) intervention on a psychiatric ward; (2) explore whether EBCD can be successfully implemented in this setting; (3) measure the impact of EBCD in terms of the ward atmosphere; and (4) explore the role and impact of a service user group (Research Net) leading the implementation of EBCD.

Methods

A multiple methods study, including non-participant observation of key EBCD events (approximately 11 hours) and 18 semi-structured interviews with 11 participants in the EBCD events. Observational and interview data were analysed using thematic analysis. The Ward Atmosphere Scale (WAS) survey instrument was fielded on the ward both before and after the EBCD intervention and analysed using an unpaired t-test.

Findings

Awareness of EBCD varied between staff and members of Research Net; Research Net were optimistic that EBCD would improve care, staff were pessimistic. Nonetheless, EBCD caused anxiety for both staff and Research Net. Co design helped break down barriers but highlighted power imbalances between staff, managers and service-users. Adhering to the EBCD toolkit enhanced likely success of EBCD implementation but adaptations were required in a mental health setting. There were significant differences pre/post intervention on the WAS for patient experiences ($p < 0.005$) of the ward but not for staff experience ($p < 0.04$). Benefits and concerns were raised regarding the role of Research Net in implementing EBCD.

Conclusions

EBCD can be successfully implemented in a mental health setting. Service-user leadership of the project was positive, but more consideration needs to be given to fully involving staff in the process.

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Chapter 1

Background

1.1. A brief history of acute mental healthcare provision

Mental illness has a high prevalence in society today; in the UK one in four members of the general population experiences a diagnosed mental illness yearly (Singleton et al, 2003). A recent report from the London School of Economics has highlighted that among the adult population under 65, half of all (diagnosed or undiagnosed) illnesses are mental illnesses (LSE, 2012). Mental health care in the UK is currently provided both in the community and in hospitals.

In the UK in the nineteenth century mental health care was provided in asylums (Foucault, 1977). The asylums were a philanthropic reform in the Victorian era following the exposure of dreadful abuse in the private madhouses. A report to parliament gave rise to the County Asylums Act in 1808 (McCrae & Nolan, 2015) and following this the first public asylums began to appear. McCrae and Nolan (2015) explain that the asylum movement was the result of two opposed socio-political aims that led to the same outcome; firstly, philanthropic reformers who wanted better conditions for the large numbers of people living in poor conditions across the country, and secondly, in an increasing catalyst economy that needed a large supply of manual labour, there needed to be a system that organised those who could not work. The asylums were originally built as curative institutions but this soon became impossible due to overcrowding; indeed, the number of 'lunatics' per 10,000 people in England and Wales rose from 12.66 in 1844 to 24.13 in 1870 (Jones, 1972). The reason for this increase has been extensively debated but for sociologist Andrew Scull the Industrial Revolution created thousands of social casualties, many of whom ended up in asylums (Scull, 1977). Treatment in asylums continued in this vein up until the early twentieth century but a seed of change emerged in 1907 when Henry Maudsley gave a gift of money to the London County Council. Maudsley stipulated that the funds be used for the development of a hospital that would deal exclusively with early and acute cases of mental illness and have an out-patients department (Jones, 1972). Maudsley's ideas were translated into policy with the 1930 Mental Treatment Act which renamed asylums as 'mental hospitals' and stipulated that lunatics should be called 'persons of unsound mind'. The Mental Health Treatment Act also introduced voluntary admission for people with acute mental disorder and led to the development of separate acute admission

units; however, most patients still remained certified until 1960 (under the 1890 Lunacy Act) (McCrae & Nolan, 2015).

After the Second World War and the inception of the National Health Service in 1948 life continued in mental hospitals largely as before. However, many medical superintendents in charge of the mental hospitals began to unlock the doors in an attempt to try to change what they saw as an oppressive and brutalised institution (McCrae & Nolan, 2015). During the 1950s many new treatments began to be developed that could contribute to the treatment of the mentally ill including, for example, insulin coma therapy, psycho-surgery or lobotomies, electric convulsive treatment (ECT) and medications such as chlorpromazine (McCrae & Nolan, 2015). In 1959 the 1890 Lunacy Act was replaced by the Mental Health Act which set out that mental illness should be treated as physical illness and that community services should be developed (McCrae & Nolan, 2015). This Act began the policy of deinstitutionalisation in the mental hospitals, as the government of the time, as presented by Enoch Powell in the Water Tower speech (Powell, 1961), highlighted a drive towards social and community care and asserted that care should be provided in the community wherever possible with hospitalisation as a last resort.

These deinstitutionalisation policies saw thousands of patients being released from long stay hospitals. A survey at the time commissioned by the Ministry of Health predicted that the ratio of mental hospital beds would fall from 3.1 per 1000 population in 1959 to 1.8 per 1000 by the middle of the 1970s (Tooth & Brooke, 1961). These policies were coupled with other factors that took place at this time including further pharmacological advances - primarily the development of neuroleptic drugs which enable people with serious mental illness to live in the community, (Carpenter, 2000) - but some saw them as purely financially driven (Scull, 1977) whilst others felt it was a result of a liberal backlash against the horrors of the asylum (Bushfield, 1986) and/or the result of psychiatrists demanding reform of the asylums because they felt that the effect on patients was intractable (Prior, 1991). Thus Samson (1995) describes deinstitutionalisation as an unholy alliance between liberals fighting the horrors of the asylum and fiscally motivated conservatives. But whatever the rationale for deinstitutionalisation, the effect on the asylums was great; Samson, (1995) reports that in 1955 the hospital population was 143,000 compared with only 43,000 in 1991.

In the late 1980s the intention of the government White Paper 'Caring for People: Community Care in the Next Decade and Beyond' (Department of Health, 1989) was that mental health care would move from the small psychiatric units that had been set up to replace the asylums into people's homes (Quirk and Lelliott, 2001). However, the

decline in the number of NHS beds for mentally ill people has not been matched by an increase in residential beds in other settings (Sainsbury Centre for Mental Health, 1998), meaning demand on services has increased along with rates of admission (Lelliott, 1996). These admissions are also usually involuntary and unplanned, and often made compulsorily under the Mental Health Act (Audini et al 1999; Ford et al, 1998).

This increased demand on mental health services has resulted in several impacts on wards; surveys have indicated there are problems of violence (Royal College of Psychiatrists, 2007), and that illicit drug and alcohol use is common, (Barker, 2000); the scarcity of beds has also often meant that patients are often transferred to distant hospitals far from their family and friends (Mental Health Crisis Care Concordat, 2014).

1.2. Service user experience of acute inpatient mental healthcare

Despite the dramatic fall in bed numbers psychiatric hospital care is still a major component of mental health provision in the UK. It is also reported that they remain often frightening places to be (Hiatt, 2010; Gould, 2011). Indeed, the threshold for admission is now so high that it is only the most disturbed cases that are admitted (McCrae and Hendy, 2016). There is an acknowledged increase of the demand on wards and the impact that these demands have on patient care. Service users are often asked to fill out satisfaction surveys; however, these seldom go beyond asking what was good and what was not, (Bevan et al, 2007). Previous attempts to change the culture of psychiatric wards have aimed to improve efficiency from a staff perspective with the ostensible aim of increasing time for direct patient care; perhaps the most well-known of these is the Productive Ward scheme (NHS Institute for Innovation & Improvement, 2008).

Psychiatric wards are often people's first point of contact with mental health services and reports suggest that people's experience of receiving care from psychiatric wards is mixed. There is a great deal that could be done to improve people's experience of receiving care on psychiatric wards (Sainsbury Centre for Mental Health 2005) as acknowledged in government reports (for example, The Health Care Commission, 2008) which argue that - although there are pockets of good practice - there is still much that can be done to improve psychiatric inpatient care. The recommendations of several official reports call for service users and their carers to be involved in the ongoing development process of the way that psychiatric hospitals deliver care. However, the user experience is particularly hard to improve because so many different

types of crises converge; safety has to be a high priority and this inevitably impacts on civil liberties. On the staff side, ward staff experience high levels of violence and complaints with 49% reaching a threshold of burnout/emotional exhaustion, resulting in sickness and retention problems (Totman et al, 2011). Senior Trust managers must account for their wards but it is difficult to understand the underlying issues causing such issues from the available crude measures (such as incident reports and complaints). Furthermore, adding additional monitoring burden on staff often exacerbates the very issues being measured.

In summary, the increased demand on psychiatric wards has led to a shortage of beds across England and Wales (Mental Health Crisis Care Concordat, 2014) which has in turn led to increased pressure on staff and - often - poor quality of care for patients.

1.3. Ethnographic studies of service user experience since the 1960s

Over the past five decades of changes to mental health services, the nature of psychiatric in-patient services and how this is experienced by patients has been periodically subjected to investigation (Quirk & Lelliott, 2001). The most influential of these studies is the sociological examination of the experience of psychiatric patients in a psychiatric hospital in the USA (Goffman, 1961). Goffman explored the institutionalisation of both the patients and the staff and proposed that the experience of being in a psychiatric hospital socialises people into being a good patient; this for Goffman leads not to a cure but ironically to quite the opposite in a process that leads to demoralisation, skill deterioration and role dispossession with people being less able to manage in the outside world and preparing them only to remain within the hospital setting.

Goffman's work is reinforced by the work of Michel Foucault in his study on madness (Foucault, 1977). Foucault in his examination of psychiatric institutions in Europe discusses the 'ship of fools' as a literary device that had a real existence; towns dealt with madmen by expelling them. The expulsion of madmen involved complex symbolism; the madman had to be both excluded and enclosed. Foucault asks why, if this theme was so deeply embedded in European culture, the 'ship of fools' suddenly appeared arguing that this was due to a great uneasiness that began at the end of the Middle Ages. Madmen became dangerous and ambiguous figures; for Foucault the primary role of institutions is to remove people with mental health problems from society. Psychiatric hospitals were designed not to cure or help people but to confine them. Foucault's argument was against the ascent of reason; as the mad lack reason

therefore they were not viewed as fully human and institutions served 'to divide off' the insane from the other unreasonable groups (such as the poor, the idle and the criminal) (Foucault, 1977), thus according the insane an exclusive place amongst the excluded.

Another seminal ethnographic study of the experience of patients in psychiatric hospitals was conducted by Strauss and colleagues (Strauss et al, 1964). Strauss and colleagues' study, again in the USA, focused on how patients attempted to cope with life in hospital and their awareness of their own mental illness. From their observations researchers identified that patients thought about their mental illness in at least four predominant ways: they are (1) organically ill, (2) nervous, (3) have a specific psychological problem, or (4) have a personality problem. Staff were evaluated by patients by their ability and approach to treatment of these presentations. Strauss et al (1964) also found evidence of patients 'playing' with doctors and nurses by withholding information about how they were feeling and what they experienced in order for the patients to be able to test out the doctors ability. Strauss et al (1964) identified that patients saw nurses as little more than people who follow doctors' orders. Strauss et al (1964) work supported the work by Goffman (1961) in identifying that the experience of both staff and patients was institutional and that both groups had their roles to play within the institution; however, both studies established that the convenience of the institution came first reinforcing the notion of a good patient as one who complied.

Quirk and Lelliott (2001) argue that although these important and influential works give us a wealth of evidence about patient experience, they were undertaken in the USA and that no ethnographic research of this type has been conducted in the UK since the 1970s. Relevant studies from that time include Altschul (1972), Cormack (1976) and Towell (1975). Altschul (1972) observed nurse-patient interaction and found that this accounted for only 1% of observed time on wards, and only 30% of patients spent more than 1% of their time in interactions with nurses. Cormack (1976) also looked at the nurse patient relationship, finding that nurses - rather than providing some form of psychotherapy to patients - had a rather more limited function of obtaining information from patients to monitor them; Cormack, like Altschul (1972), observed little nurse patient contact but never-the-less patients valued this contact and nurses were viewed as positive contributors to the patient's mental health. Towell (1975) explored the complex inter-relationship between hospital organisations, treatment ideology and patient care with psychiatric nursing as the prime focus. He found that the nature of the nurse-patient relationship depended on how the nurses interpreted the meanings of patient behaviour (medical or socio-therapeutic); patients were not equally regarded as 'ill' by nursing staff and this had a direct result in the care they received (being perceived as ill, meant patients received better treatment).

1.4. Empirical studies in the UK context

The relative lack of recent ethnographic studies into psychiatric wards in the UK has meant that little is known about current patient experience on acute psychiatric wards in the UK. In the UK, the majority of studies to date have used quantitative and questionnaire surveys to understand patient experience of acute psychiatric hospitals. One example of this is the Ward Atmosphere Scale (WAS) developed by Rudolph Moos in the 1970s. The WAS is a survey tool specifically designed to rate psychiatric inpatient experience and to be completed by both staff and patients (Moos, 1974). Such questionnaires and quantitative survey-based research in the 1990s in the UK highlighted some key themes: that nurse-patient relationships are perceived to be an important aspect of psychiatric in-patient care (Rogers and Pilgrim, 1994; Higgins et al, 1999); that the contact between nurses and patients is limited, as is contact with other mental health professionals (Higgins et al, 1999; Sainsbury Centre for Mental Health, 1998); that patients appreciate and value the humane and compassionate qualities of nurses and other mental health professionals (Rogers and Pilgrim, 1994; Leavey et al, 1997); that life on a psychiatric ward is seen as unsafe and boring by patients (Ford et al, 1998; Higgins et al, 1999 and Sainsbury Centre for Mental Health, 1998); and that the conditions on wards are criticised (Barker, 2000; Quirk et al, 2000).

Whilst this research is useful in providing an overview, it offers very little in terms of understanding the experience of patients on a psychiatric ward (Quirk and Lelliott, 2001). More recently, Lelliott et al (2001) developed a tool, Carers' and users' expectations of services – user version (CUES-U), that sought to measure the issues that are important to service users; Lelliott et al (2003) also developed a similar tool, Carers' and users' expectation of services – carer version (CUES-C), to measure mental health service users' carers experience of mental health services. CUES-U was tested by 449 service users across 32 locations in England, Wales and Northern Ireland in 1999; CUES-C was then tested by 243 carers across several locations in England, Wales and Northern Ireland in 1999. The conclusions from these studies was that you could apply a service user and a carer rated tool, that was valued by service users and carers, to measure service user and carer experience of mental health services., service users and carers found the tools easy to understand and not difficult to complete. Cues-C and Cues-U. have been evaluated in subsequent studies (Coker et al, (2015); Harvey et al, (2008); Macpherson et al, (2005); Noble and Douglas, (2004) and Quirk et al, (2009)), which found that CUES-U & C could aid care planning in mental health care and that CUES-U could provide a useful bench mark of service users experience of mental health services.

To develop a greater understanding of the experience of everyday life on a psychiatric ward for patients it is useful to look to studies specifically designed for this purpose. The ethnographic studies of Goffman and Strauss have previously been highlighted as giving a good insight into the experience of patients; however, these were both in the USA and in the 1970s and provide limited understanding of the experience of patients in today's acute psychiatric wards in the UK. As there has been limited research of this type in the UK, it is relevant to look at other more recent international studies. Barret (1996) combined ethnography and discourse analysis to explore life on a psychiatric ward in an Australian hospital, examining the practices of a hospital multidisciplinary team (MDT) and how this affects patients' outcomes. Barret (1996) argued that transforming a patient from a 'case' of schizophrenia to a 'moral agent' is the prime object of treatment and that the professional talk in the MDT is pivotal to this process.

Discourse analysis studies, along with ethnographic studies, have rarely been used in the UK to examine acute psychiatric wards, indeed none since the introduction of community care in the UK. Quirk & Lelliott (2001) argue that this is because the attention of health service researchers has moved from hospital care into community based mental health care. There is limited published research on the experience of patients on psychiatric wards after the early 2000s; the research that does exist highlights problems of violence (Warren & Beardsmore, 1997; Sainsbury Centre for Mental health, 1998), problems of sexual harassment (Barker, 2000), increased alcohol and illicit drug use (McGeorge & Lelliot, 2000) and high staff turnover and extensive use of bank and agency staff with permanent staff experiencing low morale (Ford et al, 1998). Quirk et al (2006) conclude that psychiatric wards have become 'permeable' to the outside world and are no longer the 'asylums' they once were; membership of the ward, for both staff and patients is temporary, stays on the ward are short, and there is high staff turnover. To improve this for a more positive patient experience, stays should be longer, with more permanent staff. However, in today's fiscally challenged NHS, this is far from easy to achieve; there are less nurses training and psychiatric beds in the UK are reducing with demands for admissions to be ever shorter. Quirk & Lelliott, (2001) conclude that in terms of the research they reviewed, the focus was very much on the clinical practice of the mental health professionals and there was a clear need for further research involving patients to understand how care is delivered on acute psychiatric wards.

Interviews with patients have highlighted the key role that both the environment and the relationships with mental health professionals have in the patients experience on a psychiatric ward (Bristol Mind, 2004; Rose, 2001). A more recent interview study with patients found that the relationships patients formed whilst on the ward were central to

patients experience of a psychiatric ward (Gilbert et al, 2008). Gilbert et al (2008) found that these relationships were key and could both positively and negatively affect a patients' experience of a psychiatric ward, concluding that the user led nature of their research creates a richer understanding of the patients' experience of receiving care and is vital in expanding the evidence base in both psychiatric and health service research.

1.5. Improving healthcare quality

Improving the quality of health services is a complex task; NHS staff in England are expected to deliver improvements to patient care in times of great financial and work load pressure including increasing demand (Health and Safety Executive, 2015). In order to meet these challenges, it is vital that there is a commitment to a strategy of quality improvement that delivers better outcomes for patients and staff for lower costs and a key component of this involves redesigning how services are delivered (King's Fund, 2016). Government policies in the UK have sought to improve the quality of care in the UK for several reasons; as a response to well documented failures in patient care in the UK; concern from citizens about variations in performance; that the UK had fallen behind other parts of the world in key health indicators, such as cancer survival rates; and as well as a general sense that the NHS could do more to improve patient safety and quality (King's Fund, 2016).

UK government policies that moved the NHS towards a quality improvement (QI) agenda began in earnest in the late 1990s with Tony Blair's Labour government. Key policy documents of the time included 'A First Class Service' (Department of Health, 1998) and 'An Organisation with Memory' (Department of Health, 2000) which identified that the NHS should learn from its mistakes and critical incidents. Following on from these and other policies the National Institute of Clinical Excellence (NICE) was founded to promote and develop national standards of clinical care; inspectors of health care providers were established (currently the Care Quality Commission (CQC)), performance metrics and targets were increasingly introduced to measure and monitor specific aspects of quality (e.g. waiting times) and a range of different NHS quango's were introduced to oversee this new area of work (King's Fund, 2016).

The majority of QI methods were originally developed in industry and have been imported into other sectors, such as healthcare. These techniques and methods have been used within healthcare over the last 15-20 years but often not consistently and so evidence as to their effectiveness is limited (The Health Foundation, 2016). The

reasons for this are varied; fidelity to QI methodology is variable, QI projects are often small time-limited projects led by clinicians who lack expertise and power to implement changes, and too often the QI interventions are seen as 'magic bullets' that can solve everything (Dixon-Woods & Martin, 2016). A range of methods have been used from utilising processes that eliminate waste and focus on the processes to ensure efficiency (such as the lean processes that the Virginia Mason Hospital in Seattle have used effectively (Kenney, 2010)), to focusing on continuous improvement by implementing plan, do, study, act (PDSA) cycles to continually focus on making improvements, and more recently to co-designing or co-producing services with health care users.

1.6. Service user involvement, co design and co-production of healthcare services

The highlighting of the value of patient involvement in the design of services is repeated in several key UK health service policy documents (see Department of Health, 2005) pointing to a growing awareness over the last decade of the significance of the patients' experience in terms of quality; for example, Darzi, (2008) states that patient experience should be fundamental to designing future services. However, how patient experience should be heard or used in the redesign of health services is unclear (Dewar et al, 2009). More recently the Francis report into what happened in the Mid Staffordshire NHS Foundation Trust (Francis, 2013) highlighted the serious problems that can result of not putting patients at the heart of how services are delivered. In response, the recent NHS England report, 'Putting Patients First' (NHS England, 2013) highlights the desire to correct this by acknowledging that historically services have often been designed around the needs of staff rather than patients. Davies et al (2004) found that patient-centred care was less advanced in the UK, than in other countries, coming below Australia, Germany and New Zealand.

Co-production or co-design is becoming an increasingly common methodology to improve quality. Co-production means that the public are involved in the creation of public policies and services; not only are the public consulted but they are an integral part of the conception, design, steering, and management of services (Bason, 2010). Co-design is a specific form of co-production where design thinking, tools and processes empower and guide service users to help providers develop solutions or improve services by working together. Experience-Based Co-design (EBCD) is a form of co-design specifically adapted to use in the healthcare sector (Bate and Robert, 2007; Robert et al, 2015). EBCD is an approach to improving patients' and staff experience by enabling staff and patients to work together in partnership to design

services. Experiential data are gathered through in-depth interviews, observations and group discussions and analysed to identify 'touch points'; the aspects of a service that are emotionally significant. Staff are shown an edited film of patients' stories about their experiences before staff and patients come together in small groups to develop, implement and evaluate service improvements (King's Fund, 2013).

1.7. Service user involvement and co design in mental health settings

The nature of service user involvement in research in mental health settings has been contested, most mental health research studies have not used outcomes that are valued by service users (Simpson and House, 2002). Repper and Perkins (2007) attribute this relative neglect to the clinicians or mental health professionals' presumption that mental health service users suffer "lack of insight". Many mental health service users have expressed profound anger at their treatment by services, indeed a Psychiatric Survivors Movement was formed by service users who felt that despite the poor treatment they had received from mental health clinicians and mental health services, they had managed to survive (Morrison 2005).

The service user perspective has been viewed as a mark of validity in research, freeing the user experience from the oppression of professional narrative (Thornhill et al, 2004). This has been productive, showing that mental health service users - unsurprisingly - typically prioritise differently from professional research, emphasising non-medical aspects of mental health such as social context, self-help and recovery (Rose et al., 2010). Rose et al., (2010) found many service users saw professional research as biased and driven by career advancement, power and control; they recruited a local service user group, the Consumer Research Advisory Group (CRAG), to design a questionnaire and carry out interviews with service users about what they felt should be improved. CRAG looked into mental health service users' priorities for research and found that despite all the research that had been undertaken to improve mental health services, they failed to see the link to any practical improvements in service delivery for service users. Nonetheless, service user input has broadened the notion of mental health from a purely disease-health paradigm; for example, in 2005 the National Institute for Mental Health England endorsed the recovery model for mental health services and published a guiding statement on recovery (NIMHE, 2005). This statement was based on the principle that the notion of recovery in mental health is based on what has helped service users rather than what mental health services do for people.

The recognition of the potential contribution of service user experience has arrived relatively late in mental health services; research has tended to seek to separate the service user voice from the provider population. There have been calls for a broader, multiple-research paradigm that looks to enable the use of both professional and service user evidence to develop best practice to improve mental health services (Bracken & Thomas, 2001; Clark & Chilvers, 2005; Rose et al, 2006). Yet mental health service users and the provider populations do not have much history of co-operation on which to draw. Contemporary studies often highlight the power dynamics involved in taking a co-design approach to mental health. Gillard et al., (2012) undertook a reflexive study of a service design in a south London NHS mental health trust and found that its effectiveness was determined not only by identifying consensus between user and provider views but also by explicitly stating that validity would be determined by neither side involuntarily subordinating its view for the other. The relationship between power and knowledge in mental health services is marked and there are key distinctions in the different positions in this regard between service users and staff, this theoretical framework will be explored in more detail in chapter 2, the literature review chapter,

The purpose of this study is to examine whether co-designed services could improve the outcomes and experience of psychiatric patients and staff. The overall aim is to explore and evaluate the impact of a service-user led co-design intervention to improve service user and staff experiences on an adult acute psychiatric in-patient ward. The next chapter will explore the literature relating to the use of EBCD as a QI approach in mental health settings.

Chapter 2

Literature Review

2.1. Review Question and purpose

To conduct a narrative review of the literature which explores the effectiveness of service user led QI interventions in mental health settings.

This review aimed to understand the evidence relating to the contribution of service user experience to improve the way mental health inpatient services are delivered. A specific focus was to establish whether there was any existing evidence exploring the experience of participating in an EBCD process; both for patients and staff. The review was undertaken to inform a mixed methods study exploring the contribution of EBCD to the improvement of mental health inpatient services and how that process is experienced by patients and staff. The EBCD approach itself is described in more detail in Chapter 3.

2.2. Approach to the review

Given the review question and existing knowledge of the evidence base, a narrative approach was taken as a conventional systematic review was not appropriate given the predominantly qualitative and exploratory state of the topic area. A search of previous literature reviews on the Cochrane Database of Systematic Reviews (CDSR) and other electronic sources did not identify any relevant reviews. A narrative review was appropriate to review the evidence as it enables a summary from different primary sources to be brought together with the reviewer's own experience of the area to form an holistic interpretation of the subject matter, (Campbell collaboration, 2001; Kirkevold, 1997). The author chose this form of review as it allowed him to bring his own prior experience of participating in a service user led QI intervention into the review process together with an exploration of different aspects of service user participation in other QI interventions. Four key subject areas were explored in the review; service user led research, participatory action research, EBCD and EBCD in a mental health setting.

My study centred on a service user led quality improvement (QI) project, which had four aims; 1) to study the implementation of a service user led QI project, 2) to see

whether the project could be implemented in a mental health setting, 3) measure the impact of the QI intervention and 4) to explore the role and impact of the service user group in leading the QI project. To inform my empirical fieldwork, it was necessary to undertake four discrete but closely related literature reviews. I firstly reviewed what is already known about the processes and impacts of service user led research, in all healthcare settings, to inform both the broad design of my study and so that I could consider my subsequent findings in the context of this wider knowledge. The second area I explored in reviewing the literature was that of participatory action research (PAR), again in all healthcare settings, as this is cited by Bate and Robert (2006) as being a set of methods that underpin EB CD. The third literature I reviewed was that which specifically related to Experience-based Co-Design (EB CD) itself (the particular QI method I would be studying), both in terms of what is known about how EB CD has been implemented in health care settings previously and what, if any, impact it has had. Finally, I sought to review any relevant literature directly concerning the adoption and implementation of EB CD in a mental health setting; this was the specific context in which my own study was undertaken (although it became apparent that the literature in this regard was extremely limited).

2.3. Methods

This review of the literature covered the period from 2004-2016. This twelve-year period was considered adequate as it spans the period when Experience Based Co-Design (EB CD) was first developed and piloted in health care up to the present day.

2.3.1. Criteria for considering studies for this review – Inclusion criteria

- All empirical studies and designs were included.
- Studies including health care professionals and service users (either in the process of research or more specifically in an Experience-based Co design project) in a health care setting.
- Published from 2004 to 2016.
- Published in English language peer reviewed journals.

2.3.2. Search methods for identification of studies

The following electronic bibliographic databases were searched (January 2004 – June 2016) using a detailed search strategy to identify potential papers for inclusion:

- British Nursing Index (BNI) 2004 to 2016
- CINAHL in EBSCO Host Publication date 2004 to 2016

- PsychINFO in Ovid SP 2004 to 2016
- PsychARTICLES in Ovid SP ® 2004 to 2016
- Web of Science 2004 to 2016

Four separate searches were run within the databases; service user led research; action research; EBCD in a non-mental health setting and EBCD in a mental health setting. The search strategy can be seen in appendix 1.

In order to retrieve any relevant unpublished studies contact was also made with 3 leading researchers and practitioners in the field who were known to have expertise in this area.

The reference lists of all relevant studies were all checked to examine whether any other previous studies should be included in the review.

2.3.3. Selection of studies

Title and abstracts of all studies identified by the searches were retrieved and reviewed by AG who excluded all irrelevant papers. It was not possible to have additional reviewers as the review was completed as part of a doctoral program. Studies were categorized into 'excluded' and 'included' categories.

2.3.4. Data extraction and management

Studies not excluded at this point were retrieved in full text and assessed for eligibility. The main review author (AG) developed and applied an eligibility checklist; the papers subsequently selected were then quality appraised using the CASP (Critical Appraisal Skills Programme) (CASP, 31/05/13) tool for qualitative studies to assess their methodological quality. The CASP tool is a well-known and used appraisal tool. CASP is a UK originated project that's aim is to help clinicians and managers in health services develop skill in the critical evaluation of clinical effectiveness.

2.3.5. Findings

To structure the presentation of the findings of the narrative review the following subsections are used:

- Service user led research
- Participatory Action research
- EBCD in non-mental health settings
- EBCD in mental health settings

2.4. Service User led research

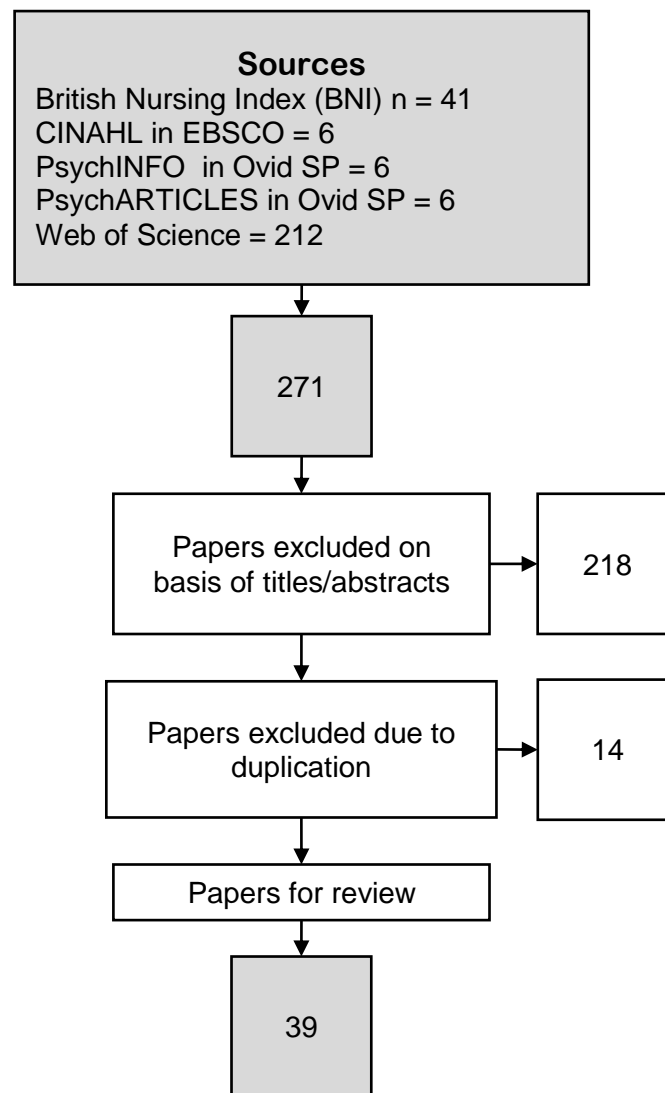


Figure 2-1 Data search and retrieval process for service user lead research

Figure 2-1 shows the data search and retrieval process for the review on service user led research.

2.4.1. Description of studies

The searches identified a total of 271 papers. Titles and abstracts of these studies were retrieved and reviewed and appropriately excluded using the following further eligibility criteria:

- Did service users participate in the leading of the research?
- To be excluded if service users are only part of a focus group or being

A total of 39 papers met the inclusion criteria (39 qualitative studies and 0 quantitative studies) and were appraised against the CASP qualitative research checklist. Most

studies were able to fully address seven (7) or more of the ten (10) appraisal questions (see Appendix 1). This provided a good indicator that the studies incorporated within the review were of good methodological quality with no studies of poor methodological quality

The 39 qualitative papers on service user led research come from a variety of settings; adult mental health (Forthergill et al, 2012; Gale et al, 2012; Nicholls, 2007; Taylor et al, 2012), neuro rehabilitation (Pound, 2011), geriatrics (Cornes et al, 2008), child and adolescent mental health (Fallon et al, 2011), palliative care (Street et al, 2007), diabetes care (Lindemeyer et al, 2007), orthopedics (Lucas et al, 2013), cardiac care (Jackson et al, 2014) and physical community health care (Martens, 2011).

Despite the range of health care settings, there was consistency to the conclusions of the studies, namely that service user led research improves the way that care is delivered and also that enabling service users to lead on research “achieved clinical changes which had not occurred during previous attempts at service development” (Lucas et al, 2013, pg 140). There was a theme throughout the studies that not involving service users in all aspects of the research meant that the right questions were not always asked by researchers; indeed Taylor et al (2012) articulate that there is gap between what service users want from services and what they actually receive and that this gap cannot be bridged by merely talking to service users. This argument is supported by Jackson et al (2014, pg 224) who state “that it is vital that patients are involved in developing the questions to ensure they are understood, comprehensive and relevant.”

Many of the studies also highlight the power imbalance between staff and service users (Gillard & Stacey, 2005; Weinstein, 2006; Gillard et al, 2012; Wallcraft, 2012; Heron et al, 2012, Maconochie & McNeill, 2010, Rose et al, 2010; Beresford, 2005; Long et al, 2012), and how service users either leading or working with staff in research can help to begin to breakdown these barriers. Seven of the studies suggest that the result of service user led research is that services deliver what patients want, rather than what clinicians or managers think they want (Cheyn et al, 2012, Minogue & Girdlestone, 2010, Walsh & Boyle, 2009; Rowe, 2006; Beresford, 2005, Newbigging et al, 2013; Middleton et al, 2011). The relationship between power and knowledge in mental health services is marked and there are key distinctions in this regard between service users and staff, with those in formal positions of power (staff) are typically assumed to hold greater knowledge. Such assumptions lead to a power imbalance between professionals and service users which has meant that the direction of research is often led by professionals (Oades et al, 2010). Whilst there is increasing advocacy from

researchers to increase service user involvement to assess the quality and effectiveness of mental health services (Avis et al, 1997; Crawford, 2001); Elbeck & Fecteau, 1990; Fitzpatrick & Hopkins, 1983; Perkins, 2001 & Williams & Wilkinson, 1995), mental health professionals have traditionally dismissed service user involvement as not meaningful. Mental health managers and professionals often highlight that they want to hear the voice of the 'authentic' service user rather than those service users who put themselves forward for involvement in research (Rose et al, 2002). Beresford (2005) responds to this distinction by offering a theoretical basis for service user led research which challenges the traditional priority placed on the values of 'distance', 'neutrality' and 'objectivity' (which he argues typically discriminate against service user involvement). Beresford (2005) also explored the idea that closing the distance between direct experience and the interpretation of that experience means that it is less likely that any resulting knowledge will be inaccurate. For Beresford (2005) the direct involvement of service users in research improves the quality of the research.

Such involvement of service users as researchers is argued to have resulted in the enhancement of reliability and validity of outcome measures that measure the quality and effectiveness of mental health services, whilst also empowering the service users involved in the research, (Clark et al, 1999; McLeod & Oades, 2001; Oades et al, 2000 and Ross, 2001). Oades et al (2010) calls for a service user led approach to evaluating mental health services, in which service users are included as collaborative researchers; this approach for Oades et al (2010) would allow service users to have input into which questions are asked about services and what aspects of the services are evaluated.

However, Rose et al (2010) points to the argument that service user 'activists', or those who put themselves forward for involvement in research, are not seen as representative of the service user view; as outlined above they are viewed by managers and clinicians as negative and critical and somehow unlike the 'ordinary' service user. Rose (2002) articulated this as a 'catch 22'; if a service user is articulate and confident enough to put themselves forward for involvement in change management or research they are not viewed as representative of the 'ordinary' service user. This perception from managers and clinicians - that service users who are involved in research do not represent the 'ordinary' service user - is explored further by Rose et al (2010), who investigated service user perceptions of the outcomes of service user involvement in two boroughs in London, Rose et al (2010) interviewed 20 'activists' and 20 'non-activists', the distinction between activists and non-activists was made by the authors and used the following criteria: if they were a member of a local

user group and had attended over four meetings of their group in the last six months they were classed as activists; if not, as non-activists. The aim was to establish whether there were differences between the two groups and found that whilst 'activists' were more aware of service user groups and user involvement activity there was little difference between 'activists' and 'ordinary' patients in terms of their ability to assess the service priorities and also there was very little difference in both groups perceptions of the outcomes of user involvement in research, which asked the interviewees if they felt that user involvement can improve local services.

In order to overcome such managerial and clinical pre-conceptions of service user involvement in mental health research and quality improvement projects, it is important that specific attention is paid to the strategies employed to ensure that service user involvement is both equal and meaningful. Tees et al (2007) highlight that the stigmatising of mental health service users by mental health professionals coupled with a paternalistic approach inhibits effective and equal service user involvement. In their study of user participation in mental health decision making, Tees et al (2007) highlight that for effective service user involvement in user-led research it is key that mental health professionals rethink how power is shared between people and that for true collaboration between mental health professionals and service users, the thinking needs to shift from professional values to those of service users.

Three of the studies highlighted using Participatory Action Research - that is to say, service users and staff working together over a period of time - as a way to improve services (Wallcraft, 2012; Maconochie & McNeill, 2010; Rowe, 2006). Finally all of the studies concluded that having service users lead research or jointly participating with researchers or clinicians improves the service that is delivered.

2.5. Participatory Action research

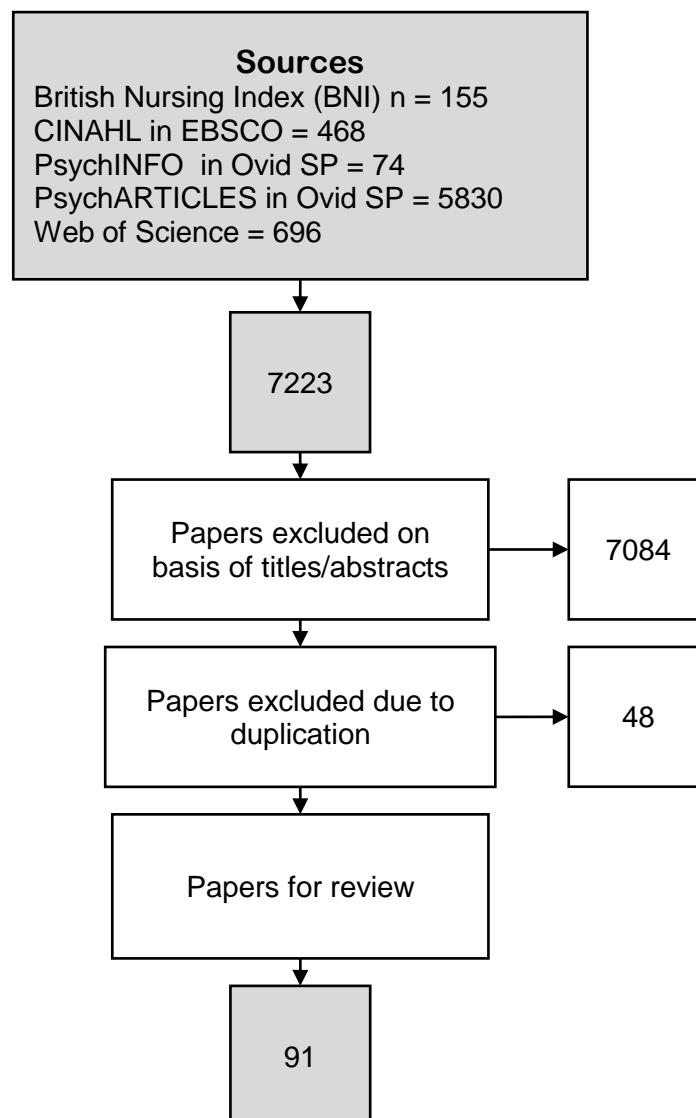


Figure 2-2 Data search and retrieval process for the review on participatory action research

Figure 2-2 shows the data search and retrieval process for the review on participatory action research.

2.5.1. Description of studies

The searches identified a total of 7223 papers. Titles and abstracts of these studies were retrieved and reviewed and appropriately excluded using the following eligibility criteria checklist.

- Was the research actually participatory action research?
- To be excluded if service users are only part of a focus group or being interviewed

The definition of what participatory action research is taken from Wadsworth (1998) who states that Participatory Action Research (PAR) in its simplest terms is an approach that involves researchers and participants working together to look at a problematic situation or process with the aim to facilitate change to make improvements in the area. This is expanded by McIntyre (2008) who describes four major components of a PAR project;

1. A collective commitment to investigate an issue or problem
2. A desire to engage in self and collective reflection to gain clarity about the issue under investigation
3. A joint decision to engage in individual and/or collective action that leads to a useful solution that benefits the people involved
4. The building of alliances between researchers and participants in the planning, implementation, and dissemination of the research process

A total of 91 studies met the inclusion criteria, based on Wadsworth's (Wadsworth, 1998) definition of the major components of PAR. These studies came from a variety of settings and will be presented in Table 2-1.

Considering the wide range of clinical areas that the studies encompassed, it is notable that they overwhelmingly concluded that PAR led to improvements in patient experience, clinical outcomes and service improvements; indeed, only one study (Petersson & Blomqvist, 2011) concluded that PAR made no difference in a dementia care setting. Details of the improvements that PAR made are presented in Table 2-2.

The next tables will be more detailed and will give some examples from within some the areas of improvement with multiple studies, the detail will include a brief description of the study and of the specific improvement made. The first two area of improvement through a PAR intervention were patient and carer experience, Table 2-5 gives more detail to two of the studies that highlighted that patient and career experience were improved because of a PAR intervention.

Table 2-1 Details of healthcare setting for PAR interventions

Health care setting	Studies
Cardiac care	Shuldham, (2013)
Community Health	Bruce et al, (2012); Lavoie et al, (2005); Janssen et al, (2013); Ravesloot et al, (2007) and Reed & Hocking, (2013)
Diabetic care	Williams, (2009)
Emergency care	Van Loon et al, (2004);
Geriatrics	Baur & Abma, (2012); Caine, (2014); Day et al, (2009); Garner & Faucher, (2014); Jones, (2015); Petersson &

	Blomqvist, (2010) and Smith et al, (2010);
HIV care	Mackoff et al, (2013); Richter et al, (2013) and Rosenthal & Khalil, (2010)
Intellectual disabilities	Read et al, (2013); Stevenson, (2014) and Walmsley & Mannan, (2009)
Intensive care	Zaforteza et al, (2010)
Mental health	Barker & Procter, (2013); Castillo, (2013); Clements, (2012); Corrigan et al, (2013); Delman, (2012); Ditrano & Silverstein, (2006); Harrison & Brandling, (2009); Hitchen et al, (2011); Hodge, (2009); Karbon et al, (2013); Lind, (2006); Michaelsen et al, (2007); Park et al, (2014); Pelletier et al, (2014); Schwartz et al, (2013); Simich et al, (2009); Speers & Lathlean, (2015); Stickley et al, (2010); Ward & Bailey, (2013); Watson & Douglas, (2012)
Neuro rehabilitation	Gauld et al, (2011) and Hebblethwaite & Curley, (2015)
Nurse education	Dyness et al, (2013); Ferreira et al, (2015); Reiersen et al, (2013); Somerville & Brown-Sica, (2011) and Storch et al, (2009)
Obstetrics	Harvey & Holmes, (2012);
Oncology	Abad-Corpa et al, (2013); Bakker et al, (2010); Wang & Chow, (2006); White & Verhoef, (2005);
Palliative care	Chowns, (2009); Dosser & Kennedy, (2014) and Loeb et al, (2013)
Public health	Aronowitz & Eche, (2013); Balcazar, (2009); Campbell, (2006); Caxaj et al, (2013); Chirewa, (2012); Duffy, (2011); Duffy et al, (2013); Etowa et al, (2007); Fine, (2013); Findholt et al, (2011); Keygnaert et al, (2014); Khailkaew et al, (2008); Kramer-Roy, (2012); Li et al, (2012); Loigon et al, (2013); Loigon et al, (2015); Lorenc et al, (2013); Lorenzo et al, (2007); Maciver et al, (2013); Martin et al, (2009); Martin et al, (2010); McDonald et al, (2012); Mckeown et al, (2012); Morton, (2012); O'Neill et al, (2004); Rattanagreethakul et al, (2010); Sabo et al, (2013); Schinke et al, (2010); Smith, (2005); Sormunen et al, (2013); Sullivan et al, (2008); Wang et al, (2010); Wang & Pies, (2004)

Table 2-2 Details of improvement made following PAR intervention

Improvements made through PAR	Studies
Patient experience	Hodge, (2009); Baur & Abma, (2012) and Read et al, (2013)
Carer experience	Chowns, (2009); Garner & Faucher, (2014) Jones, (2015)
Increased awareness of what matters most to patients from disadvantaged communities	Aronowitz et al, (2013); Baker & Procter, (2013); Bakker et al, (2010); Balcazar et al, (2009); Campbell, (2006); Caxaj et al, (2013); Chirewa, (2012); Clark et al, (2013); Corrigan et al, (2013); Ferreira et al, (2015); Fine, (2013); Harrison & Brandling, (2009); Hitchen et al, (2011); Keygnaert et al, (2014); Khaikaew et al, (2008); Li et al, (2012); Lind, (2006); Loeb et al, (2013); Loigon et al, (2013); Loigon et al, (2015); Lonrenc et al, (2013); Lorenzo et al, (2007); Maciver et al, (2013); McDonald et al, (2012); Michaelson et al, (2007); O'Neill et al, (2004); Rattanaagreeethakul et al, (2010); Reed & Hocking, (2013); Reiersen et al, (2013); Sabo et al, (2013); Schinke et al, (2010); Simich et al, (2009); Smith, (2005); Sormuren et al, (2013); Stevenson, (2014); Stickley et al, (2010); Van Loon, (2004); Wang et al, (2004); Ward & Bailey, (2013); Watson & Douglas, (2012); White & Verhoef, (2005); Williams, (2009) and Zaforteza et al, (2010)
Improvement in physical health	Ravesloot et al, (2007)
Reduction of stress in clinicians	Lavoie-Tremblay (2005)
Improved health outcomes	Castillo, (2013); Clements, (2012); Corrigan et al, (2013); Day et al, (2009); Ditrana & Silverstein, (2006); Dosser & Kennedy, (2014); Dyess et al, (2013); Duffy, (2011); Duffy et al, (2013); Findholt & Michael, (2011); Gauld et al, (2011); Harrison & Brandling, (2009); Harvey & Holmes, (2012); Hebblethwaite & Curley, (2015); Karbon et al, (2013); Khaikaew et al, (2008); Kramer-Roy, (2012); Lind, (2006); Loeb et al, (2013); Loignon et al, (2013); Lorenzo et al, (2007); Martin et al, (2009); Martin et al, (2010); McKeown et al, (2012); Michaelsen et al, (2007); O'Neill et al, (2004); Rattanaagreeethakul et al, (2010); Richter et al, (2013); Schwartz et al, (2013); Shulldham, (2013); Simich et al, (2009); Smith et al, (2010); Storch et al, (2009); Sullivan et al, (2008); Van Loon et al, (2004); Wang & Pies, (2004); Wang et al, (2004) and Williams, (2009)
Increased patient empowerment	Aronowitz et al, (2013); Baker & Procter, (2013); Bakker et al, (2010); Balacazar et al, (2009); Bruce

et al, (2012); Campbell, (2006); Castillo, (2013); Caxaj et al, (2013); Chirewa, (2012); Clark, (2013); Clements, (2012); Delman, (2012); Duffy et al, (2013); Karbon et al, (2013); Kramer-Roy, (2012); Janssen et al, (2013); Li et al, (2012); Lind, (2006); Loeb et al, (2013); Lorenzo et al, (2007); Maciver et al, (2013); Mackoff et al, (2013); Martin et al, (2010); Mckeown et al, (2012); Morton, (2012); Park et al, (2014); Pelletier et al, (2014); Reed & Hocking, (2013); Richter et al, (2013); Rosenthal et al, (2010); Sabo et al, (2013); Schwatz et al, (2013); Smith, (2005); Somuren et al, (2013); Speers & Lathleen, (2015); Walmsley & Mannon, (2009); Wang & Chow, (2006); Watson & Douglas, (2012) and Williams, (2009)

Improved health service Abad et al, (2013); Blomqvist; Caine, (2014); Shuldham, (2013) and Somerville & Brown, (2011)

Table 2-3 Range of outcomes

Type of outcome	Studies
Improved recovery	Castillo, (2013); Hebblethwaite & Curley, (2015); Karbon et al, (2013); Lind, (2006); Michaelsen et al, (2007); Schwartz et al, (2013); Simich et al, (2009);
Increased patient empowerment	Aronowitz et al, (2013); Baker & Procter, (2013); Bakker et al, (2010); Balacazar et al, (2009); Bruce et al, (2012); Campbell, (2006); Castillo, (2013); Caxaj et al, (2013); Chirewa, (2012); Clark, (2013); Clements, (2012); Delman, (2012); Ditrana & Silverstein, (2006); Duffy, (2011); Duffy et al, (2013); Karbon et al, (2013); Kramer-Roy, (2012); Janssen et al, (2013); Li et al, (2012); Lind, (2006); Loeb et al, (2013); Lorenzo et al, (2007); Martin et al, (2010); McKeown et al, (2012);
Reduction of stigma	Corrigan et al, (2013);
Improved physical health	Day et al, (2009); Findholt & Michael, (2011); Loignon et al, (2013); Maciver et al, (2013); Mackoff et al, (2013); Martin et al, (2009); Martin et al, (2010); Mckeown et al, (2012); Morton, (2012); O'Neill et al, (2004); Park et al, (2014); Pelletier et al, (2014); Rattanaagreethakul et al, (2010); Reed & Hocking, (2013); Richter et al, (2013); Rosenthal et al, (2010); Sabo et al, (2013); Schwatz et al, (2013); Smith, (2005); Smith et al, (2010); Somuren et al, (2013); Speers & Lathleen, (2015); Walmsley & Mannon, (2009); Wang & Chow, (2006); Watson & Douglas, (2012) and Williams, (2009)
Improved communication	Dosser & Kennedy, (2014);

between staff and patients

Improved health service

Abad et al, (2013); Blomqvist et al, (2010); Caine, (2014); Gauld et al, (2011); Harrison & Brandling, (2009); Harvey & Holmes, (2012); Loeb et al, (2013); Shuldham et al, (2011) (2013); Storch et al, (2009); Van Loon et al, (2004); Wang & Pies, (2004); Wang et al, (2004) and Williams, (2009)

Reduction in substance abuse

Khaikaew et al, (2008) and Sullivan et al, (2008)

Table 2-4 Detail of improvements through PAR interventions

Study	Healthcare area	Description of study	Description of improvement
Castillo, (2013)	Mental Health	A UK study using PAR to explore what service users with a diagnosis of personality disorder felt were the important areas of what constituted a recovery and how the therapeutic interventions in a therapeutic community could support this.	Service user contributions to what they considered to be the key steps to their recovery contributed to the way the therapeutic community was run and subsequently improved peoples' recovery.
Day et al, (2009)	Geriatrics	An Australian study that examined how older people were cared for on an acute care medical ward, 60% of older people arrived with delirium or developed incident delirium during their stay, PAR methodology was used to address this, understand what was going on and make improvements.	Through the PAR process, fewer patients developed delirium during their stay on the medical ward. PAR led to improved physical health of the older people and the early detection of delirium on the ward.
Duffy et al, (2013)	Public Health	An Australian study that used PAR to although medical students to work with local indigenous communities to improve the communities' physical health by accessing appropriate health services.	PAR intervention between local indigenous communities and a medical school empowered the local community to request what they required from healthcare providers to improve their community's health.
Harrison & Brandling, (2009)	Mental health	A UK study that used PAR intervention to improve the care of older people with mental health needs	Through PAR interventions, staff awareness of the needs of the patient population increased

		in an older people's unit of a general hospital	and changes were made to the way that services were delivered which led to an improvement in the care for older people with mental health needs in a general hospital.
Rattanagreethakul et al, (2010)	Public Health	A study in Thailand that used PAR methodology to work with families to try to prevent pre-school children from becoming overweight	PAR interventions allowed the families of pre-school children to understand the reasons their children were becoming overweight and increased awareness and understanding of the issues, the outcome of the study was that the children of families involved in the study were able to maintain a healthy weight.
Wang & Pies, (2004)	Public Health	An American study that used 'photovoice', a type of PAR intervention to allow a disadvantaged community to demonstrate what their health concerns were in their community.	The local community was able to demonstrate what mattered to them, subsequently services were adjusted accordingly and the communities health outcomes improved, the authors' concluded that the reason for the improved health outcomes was that clinician were providing what patients wanted rather than what they (clinicians) thought they wanted.

Table 2-5 PAR improvements to patient and carer experience

Study	Description of study	Description of improvement
Baur & Abma, (2012)	Study in a Dutch residential care home to look at ways to enhance residents' participation. 7 residents worked with staff to develop a joint vision as to how meals in the home could be improved.	For the 7 residents their empowerment was increased, leading to increased social identity and a defined purpose, which led to overall improvements for the rest of the residents of the care home.
Jones (2015)	Study in Canada supporting carers of patients with Alzheimers and Dementia to look at ways to improve the relationship between carers and therapists.	Carers and therapist worked together to plan the information that was given to carers. PAR found to make improvements to education sessions given to carers in a dementia care home.

The overwhelming conclusion of the studies was that PAR improved clinicians' and public health bodies awareness of what mattered to a variety of disadvantaged communities, which not only had a positive impact on health of these communities, but also had an important secondary impact of increasing awareness of health inequalities. Table 2-6 will highlight two studies that demonstrate this.

This increased awareness of the issues that really mattered to communities not only had a positive effect on patients in that their physical health was improved (Raveslout et al, 2007) but also had an impact on the clinicians providing health care, with Lavoie-Tremblay (2005) highlighting that the increased awareness and understanding of what mattered to patients reduced the stress levels in the clinicians.

Table 2-6 PAR improvements that increase awareness of health inequalities

Study	Description of study	Description of improvement
Hitchen et al, (2011)	A UK study looking at introducing self-directed support in community mental health services. Service users and carers were directly involved with researchers in the study	The PAR process highlighted the issues service users and carers faced and this increased awareness of the health matters of disadvantaged communities directly highlights the power imbalance between clinicians and patients
Etowa et al, (2007)	A Canadian study looking at using PAR in rural black communities to address health inequalities, this led to a development of a health information manual	The PAR designed manual helped to increase awareness of the inequalities and helped to reduce them

Many of the studies highlighted the improved health outcomes for patients following PAR interventions, these were from a variety of health backgrounds and a range of outcomes, Table 2-3 will highlight the range of outcomes and Table 2-4 will highlight a couple of these outcomes in more detail. Two studies from Table 2-4 highlight that using a PAR intervention allowed patients to show what was important to them, (Duffy et al, (2013) and Wang & Pies, (2004), this ability for patients to be able to articulate what they actually wanted also provided an avenue for increased patient empowerment, with patients becoming increasingly confident through the PAR process to take control of what they needed from health care providers.

A number of the studies highlight a particular PAR method called 'photovoice' as a useful method to allow disadvantaged communities to be able to tell their story (Clements, 2012; Duffy, 2011; Garner & Faucher, 2014; Hebblethwaite et al, 2015; Findholt & Michael, 2011; Martin et al, 2010; Morton, 2012; Wang et al, 2004, Wang & Pies, 2004; Watson & Douglas, 2012). Duffy (2011) described 'photovoice' as a method to better understand local realities; Chown (2009), took this further and made use of video films to enhance the telling of stories from the perspective of the children with terminally ill parents. Indeed, in all PAR, patients or service-users' narratives are described as a key element - which McIntyre (2008) supports - as people's own narratives are vital to understanding the issue under investigation.

Despite some encouraging conclusions to the PAR studies, PAR has not had a strong track record, with much of the early research being criticized for a lack of academic rigour (Robert, 2015). However, advocates of PAR argue that this does not deter from the benefits that they feel PAR brings; Wadsworth (1998) proposes that PAR "involves an imaginative leap from a world of 'as it is' to a glimpse of the world 'as it could be' "(p.6).

2.5.2. EBCD in Healthcare settings

A literature review search was carried out in July 2016 with the following databases British Nursing Index, CINAHL, PsycINFO, PsycARTICLES, Web of Science using the search terms: mental health*, "experience based co design" and "experience based design". The timeline chosen to search was from 2004 to 2016; 2004 was chosen because this was the date that the term EBCD was first piloted (Bate & Robert, 2007). No restrictions were placed on the geographic locations for the search; the only restriction placed was that the paper was in English. The numbers of papers identified are shown in Figure 2-3 below. Search strategy is in Appendix 1.

2.5.3. Screening the search results of 17

A number of papers were identified that utilised patient experience to design services in inpatient mental health teams. The majority of the papers looked at how staffing and environmental issues, such as the use of bank staff or burn out among staff could affect the patient experience, (e.g. Samarasekera, 2006; Haglund et al 2006; Totman et al, 2011); other papers explored patient experiences of specific interventions, i.e. educational or psychological, (e.g. Hatonen et al 2008; Kerfoot et al, 2012) and others merely reported observations of patients experience, (e.g Harwood et al, 2011, Belling et al, 2011).

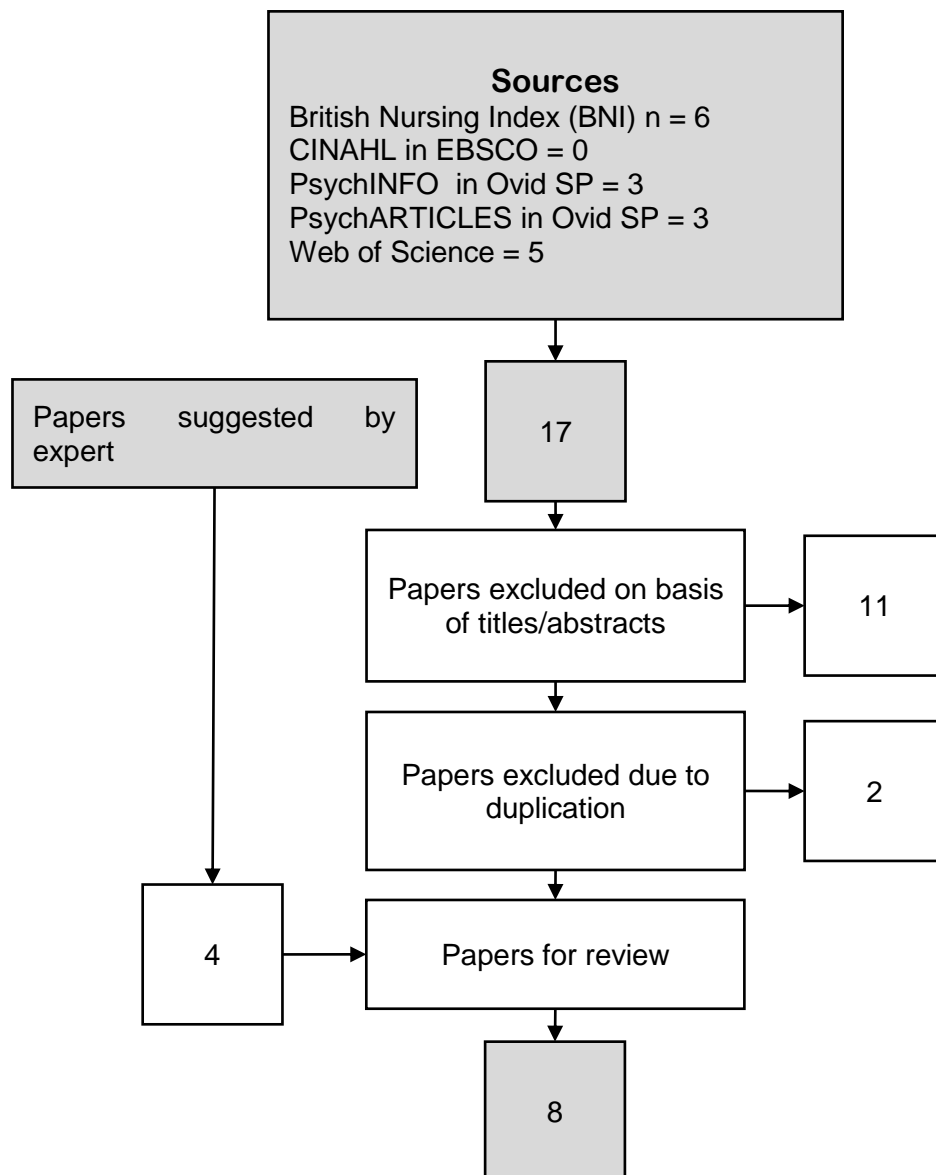


Figure 2-3 Data search and retrieval process for Mental health and experience based co design

Eight papers were found that discussed how patient experience was used to co-design mental health services (Cooper et al, 2015; Hickman et al, 2016; Hyde & Huw, 2004;

Larkin et al, 2015; Mulvale et al, 2016; Murphy et al, 2015; Palmer et al, 2016, Springham and Robert, 2015 and Wright et al, 2015); these will be discussed in section 2.7.

Due to the limited amount of literature regarding co-designing services using patient experience in the mental health setting, a further search was undertaken that did not look specifically at mental health care. The literature search was undertaken again using the same databases; British Nursing Index, CINAHL, PsycINFO, PsycARTICLES, Web of Science, but the following search terms were used; health care*, “experienced based co design” and “experienced based design”. The same geographical and time parameters were selected and again the language selected was English. This search produced 88 papers when the searches were combined and the search strategy can be found in Appendix 1, Figure 2-4, shows the data search and retrieval process for this search. Further screening of the search results to identify specific service co-design projects using patient experience revealed ten papers, (Bate & Robert, 2006; Bowen et al 2013; Boyd et al, 2012; Dewar et al, 2009; Iedema et al, 2010; Fudge et al, 2008; The King’s Fund, 2011; Locock et al, 2014; Tsianakas et al, 2012; Tsianakas et al, 2015; Tunney et al, 2014; Vennick et al, 2015 and Wolstenholme, 2010). A final paper (Donetto et al, 2014) was identified reporting EBCD practices and developments between 2005 and 2013.

Bate and Robert (2006) discuss how learning from the design sciences, such as architecture and graphic design, can assist healthcare in developing their services, thereby improving the pathways and processes which can lead to a better experience for patients. Bate and Robert (2006) introduce the notion of Experience-based Co-design (EBCD) as different from other methods of patient feedback and state that this method uses the experiences of patients to redesign services; the method puts “...the experience and goals of patients and users at the centre of the design process and on the same footing as process and clinical goals.” (Bate & Robert, 2006: 308). The authors state that - at the time of writing - this method is previously unused in healthcare that the method is transferable to healthcare. This is an academic viewpoint paper that introduces the concept of experience based design (EBD) - as it was initially called - rather than an empirical study.

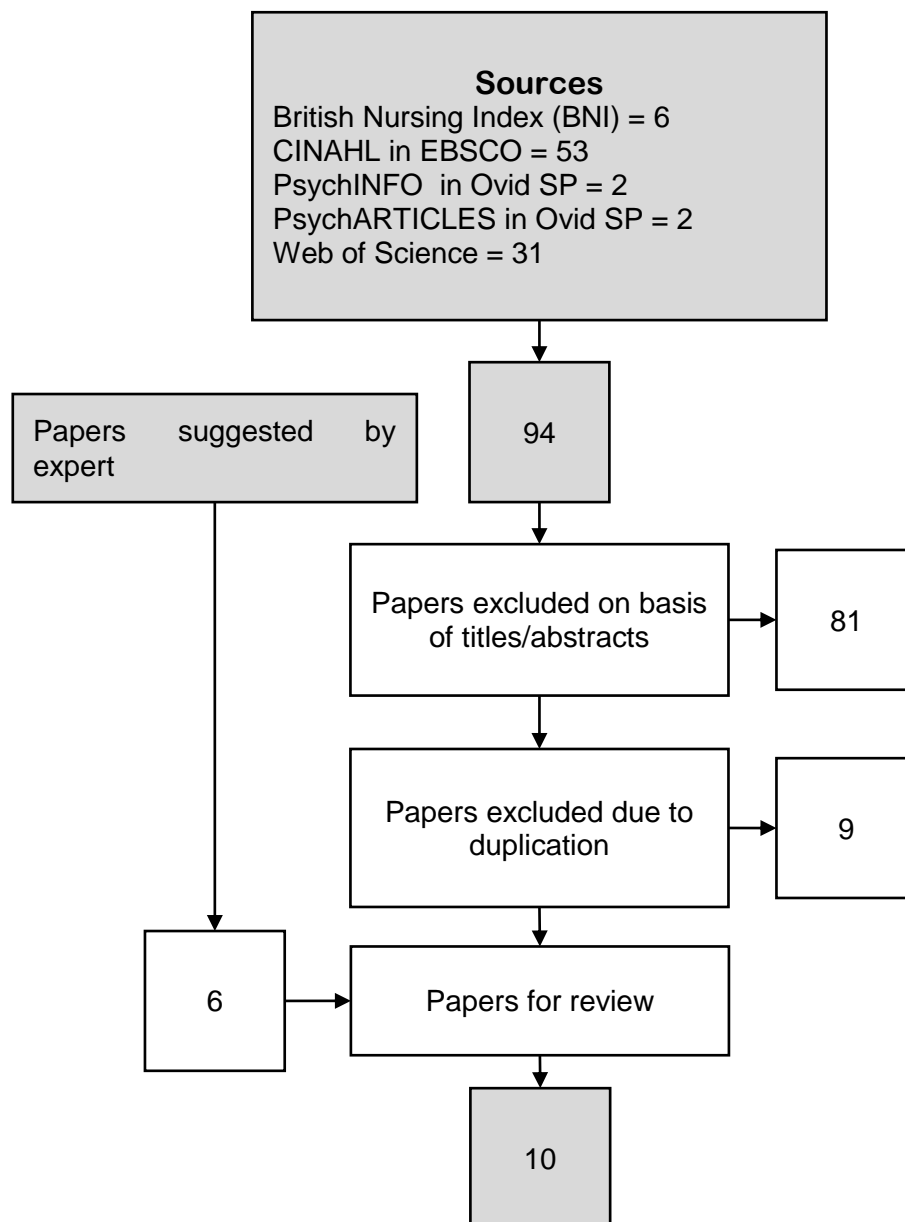


Figure 2-4 Data search and retrieval process for healthcare and experience based co design

Bate and Robert (2007) later expanded on the concept of EBCD and provided a template for methods to carry out the approach, again highlighting the usefulness and importance of using patients' experience to develop and design health services. Bate and Robert (2007) go on to state that EBCD is different from other service user led initiatives as it focuses on the concept of designing for the human experience. Bate and Robert (2007) also includes a detailed case study of the first pilot of EBCD in a head and neck cancer clinic.

Dewar et al (2009) is the first of the papers that describes the use of EBCD to improve the delivery of services. The authors asked patients to describe 'emotional touchpoints' (good and bad experiences) about their experience of being in hospital; patients' touchpoints were then transcribed into a story about their experience and these stories were then shared with staff. Dewar et al, (2009) report that - following the reading of the stories - changes came about in both how care was delivered and also how more complex aspects of care were discussed. The limitation of this study is that the authors do not indicate what structure was in place to bring about the changes; it is possible that another type of health service may not act on patient stories and care delivery remains as it originally was. This study was based on 16 patients and 12 relatives and the authors do not indicate how changes were implemented; it was a small study and results may not be transferable.

Fudge et al, (2008) present an ethnographic study into stroke services, which uses participant observation and interviews to assess user involvement in health service development; the study is based in stroke services in two London boroughs. The authors found that there was a wide range of activities that were considered user involvement; the paper did not specifically suggest a particular form of user design intervention. Whilst the authors conclude that user involvement may not automatically improve service quality, they agree with Bate & Robert (2007) that service users' experiential knowledge is valued by services because it provides information that will improve the delivery of care and thus improve patient experience.

Iedema et al, (2010) evaluated an EBCD project that took place in several Australian Emergency Departments and closely followed the principles laid out by Bate & Robert (2007). Iedema et al (2010) evaluated the project by interviewing key stakeholders. Whilst there is no assessment of whether the co-design process actually improved the way that services were delivered, the authors concluded that co-design presents opportunities to bring all stakeholders - commissioners, providers and service users - together to promote new understandings and relationships that previously were not present. The study comprised interviews with 15 staff and 10 patients.

The King's Fund (2011) is an evaluation report that describes the process and impact of an EBCD project that took place within breast and lung cancer services at two London Hospitals. This project used video recordings of patients' experience which were then played back to a mixed group of patients and staff and together they co-designed the services based on the patients' experiences. Evaluation from the project indicated greater user satisfaction with services. Exact numbers of staff and patients

were not identified and the findings may not be applicable to other health care areas, particularly mental health.

Wolstenholme et al (2010) also used the EBCD method as outlined by Bate and Robert (2007) to improve older people's out-patient services in Sheffield. The authors concluded that the outpatient experience for patients extended to beyond just the clinical encounter and to the physical building and communications from the service, both on the telephone and in letters. As with the previous highlighted papers there is no long term evaluation of whether EBCD actually improves patient outcomes; however the paper reports increased patient satisfaction following use of the methodology. The paper highlighted key areas that were important to patients although the exact numbers of staff and patients is not stated.

Tsianakas et al (2012) is a more detailed paper relating to the EBCD project described in The King's Fund (2011); the study used 36 filmed patient interviews and 63 staff interviews together with 219 hours of ethnographic observations as part of the EBCD process in breast and lung cancer services. The authors conclude that EBCD allows patients to become influential stakeholders with staff in a quality improvement process, although the authors do caution that the approach does not obtain the views of all patients and that 'harder to reach' patients' stories or views may not be heard.

Boyd et al (2012) used EBCD to improve patient experience in Breast Services in New Zealand and concluded that the approach improved patients' experience of receiving care, and that involving patients in this process is a very tangible way for health service providers to really engage patients on an equal basis to staff in how services are delivered.

In their study of using EBCD to explore carer's views into stroke services, Tunney & Ryan (2013) describe the EBCD project they implemented; the authors conclude that EBCD achieved many positive outcomes for service users and their carers, and that partnership working between patients, carers and staff can help bring about patient centred care.

Bowen et al (2013) is a post project evaluation of Wolstenholme et al (2010), and they conclude and agree with Wolstenholme et al (2010) that EBCD is an effective intervention to build collaborations between patients and service providers. The authors also point out that there was a difference in how the patients and staff described how they became involved in the project, with patients being willing participants and the staff describing that they were strongly encouraged to participate by their managers. Bowen et al (2013) report that many of the participants did not feel the project

represented good value in terms of the resources used, both time and money, to implement (with the patients in particular thinking it was taking far too long). Although EBCD was reported as improving the relationships between patients and staff, they were concerned that there was limited actual service improvement at the end of the project.

In their study, Locock et al (2014) explored using an accelerated form of EBCD in an intensive care setting and lung cancer services in two English NHS hospitals. The acceleration essentially comprised using existing pre-recorded patient experience filmed narratives from a national archive rather than recording them specifically at the intervention site. The authors concluded that agreement or identification with the films was not pivotal, that the key aspect was the staff and patients working together to co-design and that it was in the face-to-encounters that the difference was made. As Locock et al (2014: 206) state, "...patient's physical presence constantly reminds everyone who the change is for, and why it matters compared to other potentially overwhelming work pressures and demands." The authors recommend the accelerated approach as a more cost effective way of delivering patient centred quality improvement but also recommended that this is an area that needs further exploration.

Donetto et al (2014) published a report that mapped where EBCD interventions had been implemented globally and were currently being undertaken up to 2014. They identified 59 EBCD projects in over six countries and also reported that at the time of the reports publication, a further 27 projects were due to commence. The report explored researchers' and implementers' experiences of implementing an EBCD project, and reaches a number of conclusions about EBCD implementation; firstly, that there is a need for training and support to implement EBCD projects; secondly, that ethnographic non-participation observation is a crucial part of any EBCD project; thirdly, similarly the films of patients stories are crucial; and finally that the very core of the EBCD process is the co-design. The authors make a call for the need to strengthen the evidence base for EBCD.

A Dutch study explored the use and experience of EBCD in four physical health hospitals and examined why the hospitals involved staff and patients in 'co-production', (Vennik et al, 2015). The authors' concluded that EBCD contributed to quality improvement in the four hospitals. However, Vennik et al (2015) explored the hospitals motivation behind implementing EBCD as the quality improvement process in greater depth. Like Bowen et al (2013) the authors argued that the different participants in the EBCD project had different rationale for commissioning the project and being involved in the project. Vennik et al (2015) conclude that hospitals use a co-production

technique such as EBCD in order to improve the chance of the quality improvement actually happening. The authors argue that using patients in a project brings a more powerful and persuasive argument to a hospital board of why something needs to be done. The authors also feel that using patient experience via EBCD in a quality improvement project has the added benefit of providing impetus to the staff involved in the project to act on the improvement issues raised.

2.6. EBCD in mental health settings

The following eight papers explored co-production and - in all bar the first two papers - the implementation of EBCD in a mental health setting. Summary detail for these studies is in Table 2-7.

Hyde & Davies (2004) explored how services and staff patient interactions are co-produced in an adult psychiatric ward and a psychiatric rehabilitation hostel according to the demands of the service, containment in the ward, recovery to independence in the hostel and this influenced how the service ran and the language that was used; 'patient' in the acute ward and 'client' in the hostel. The authors state that co-production between staff and patients is central to any service redesign; they conclude that service user involvement via co-production is vital to improve how services operate but they state that in mental health services that co-production is a complex process, as it incorporates, the different facets of mental health care, the complex staff/patient interactions and societies demands on mental health service to forcibly detain and treat people under the mental health act. The authors conclude that co-production in mental health services may have contributed to perpetuate the regime of containment.

In a more recent paper Wright et al (2015) examined the different stakeholders' narrative about the key transition points in and out of an acute psychiatric ward. The results were that all stakeholders, ward and community staff and service users all agreed that these transition points were chaotic and stressful and that the service users' voice was lost. The authors suggest that by identifying ways in which staff and service users could work together to ensure the service user's voice is heard is key to improve the admission and discharge process for service users. The authors conclude that ensuring service users have a voice in designing how services operate is crucial; however, the authors do not propose a method to achieve this.

Murphy et al (2015) explored using EBCD in the Republic of Ireland where the goal was to improve the referral experience into a community mental health team for patients and their families. Whilst the author's concluded that using the EBCD process changed the referral process and embedded a standardized appointment process - and

service user and carer feedback described this as positive - they felt that the response rate to the surveys experience was insufficient to draw any firm conclusions. The authors did, however, feel that using EBCD demonstrated meaningful service user and care engagement in mental health services and provided a robust methodology for effective co-production.

The use of EBCD in a Child and Adolescent Mental Health Service (CAMHS) inpatient (ward) setting is explored in a study by Larkin et al (2015). Their study examines three interlinked research studies that looked at the experience of hospitalization from three different perspectives: patients between the ages of 18 and 35 (with a first presentation to mental health services and with a diagnosis of psychosis), their families and the inpatient nursing staff. The study sought to use EBCD to improve health care services for this patient group and their families. Whilst some service improvements were made, there were not as many as participants of the project would have liked to have been completed. The authors conclude that EBCD was an appropriate quality improvement methodology to be implemented in a mental health setting but that certain adaptations needed to be made, to take into account the vulnerable service user and their families groups, as well as the complex nature of mental health services. The authors found that the service user group needed a great deal of support to initially prepare them for the project as well as ongoing support during the project. The authors concluded that EBCD could be used to make service improvements in such a complex setting as inpatient mental health care but warn that comprehensive planning and senior (high level) support is required to ensure success.

Cooper et al (2015) described implementing EBCD in community psychological mental health services. The authors agree with Larkin et al (2015) that EBCD is a suitable methodology for service improvement in mental health settings and that adaptations are needed to the original EBCD approach, mainly around the filming of people's experience. The authors also found that service users required high levels of support. The study highlights that service users reported that they found the EBCD process allowed their voice to be heard throughout the process and that they felt their voice was valued; however, the study also reported that this was not the same for all staff involved in the project some of whom felt it was an intimidating process for them. The authors argue that more needs to be done to support staff through the EBCD process.

Springham and Robert, (2015) describe the implementation of an EBCD process on an acute psychiatric ward that was attracting high levels of complaints from service users and carers. The authors concur with Cooper et al (2015) and Larkin et al (2015), that EBCD is an appropriate QI methodology to be used in a mental health setting, but that

certain adaptations are required, particularly around the filming of service user experience and that service users require high levels of support during the process. The outcome of the EBCD interventions was that there were no complaints on the ward following the intervention for 23 months.

In their paper, Mulvale et al (2016) describe the conduct and findings of a systematic review of how to improve CAMH services by involving patients and their families and providers. The authors reviewed and compared 13 participatory research papers with EBCD and found that many of the studies were consistent with the core elements of EBCD, with the most common part of improving the interactions between service user and provider. The authors selected EBCD as a suitable method for quality improvement as they felt EBCD took account of the experience of all participants (staff, patients, carers and service providers). The authors concluded that the EBCD methodology was applicable to involving all participants in a CAMHS service to improve services and felt that EBCD was particularly appropriate, as it addressed the power imbalances inherent in working with a vulnerable patient population.

Finally, Palmer et al (2016) describe a large randomized control trial (RCT) study that is to be undertaken in Australia in order to test the impact of EBCD in community mental health teams. The protocol for their process evaluation to accompany the RCT is published (Palmer et al, 2016). The authors aim in this study is to advance the empirical evidence base for EBCD by examining the mechanisms of action in an EBCD intervention, exploring what the issues are for the different stakeholders and also, more crucially, whether EBCD is an effective intervention to improve psychosocial outcomes for people with severe and enduring mental illness.

Table 2-7 Summary details of EBCD studies in a mental health setting

Study	Study location	Study description	Outcome
Hyde & Davies (2004)	A UK acute psychiatric ward and a residential rehab hostel for people with long term mental illness	Observational fieldwork over a 14 month period, with observation periods of 4 to 6 weeks, also staff and patients were interviewed about their experience of receiving care and working in the environment and the researcher reflecting back to staff their impressions of the working environment.	In mental health services, services are designed in order to meet demands of that aspect of the service; containment in the acute ward, rehabilitation to independence in the hostel and that these different areas structure both how the service operates and how staff and patients interact.
Wright et al (2015)	A UK acute inpatient psychiatric ward	Seven focus groups were undertaken with ward staff, community staff and service users, to explore the nature of service user involvement in the admission and discharge process in and out of the acute ward.	The study highlights that at key transition points in mental health care the service users voice is lost, the authors call for innovative solutions to ensure that service users can influence the delivery of their care.
Murphy et al (2015)	A community mental health team (CMHT) in the republic of Ireland	Used co-production to design and test key working processes in two CMHT's to improve the experience of service users and carers seeking mental health services, used films to highlight service users experience of services.	Co-production techniques improved service user and care experience and also highlighted the complex nature of mental health service provision. Co-production was valued as important by all stakeholders.
Larkin et al (2015).	A UK Early Intervention in Psychosis (EIP) and an acute admission ward	Undertook three studies about hospitilistaion in early psychosis, using EBCD to explore the perspectives of staff, service users, carers and	EBCD was an appropriate QI methodology to be implemented in a mental health setting but that certain adaptations needed to be made and

Study	Study location	Study description	Outcome
Cooper et al (2015)	A UK community psychological therapy service	management which were then used to make service improvements Used EBCD to improve services, the process of EBCD in the setting are described as are the adaptations required in a mental health setting	comprehensive planning and senior support is required to ensure success. EBCD is a suitable methodology for QI in mental health settings and that adaptations are needed around the filming of people's experience. Mental health service users required high levels of support, but reported that they found the EBCD process allowed their voice to be heard. However, staff felt it was an intimidating process for them.
Springham and Robert (2015)	A UK study on and acute psychiatric ward	Used EBCD to reduce complaints on an acute psychiatric ward, EBCD was used to understand the issues and then to make adaptations to address the issues	EBCD required adaptations to be used in a mental health setting, support for service users, particularly around the filming. Complaints were eradicated for 23 months following the EBCD intervention
Mulvale et al (2016)	A Canadian child and adolescent mental health service (CAMHS)	A systematic review exploring how to improve CAMHS by involving patients and their families and providers. The authors reviewed and compared 13 participatory research papers with EBCD and found that many of the studies were consistent with the core elements of EBCD	EBCD methodology was applicable to involving all participants in a CAMHS service to improve services. EBCD addressed the power imbalances inherent in working with a vulnerable patient population.

2.7. Discussion: Quality of evidence in relation to stated aims

This review of the evidence of the contribution of service user experience to improve the way services on a mental health inpatient ward are delivered also sought to explore the experiences of participating in the EBCD process. The findings are limited by only one study being undertaken that focuses on the use of EBCD on a psychiatric inpatient ward (Springham and Robert, 2015). Further high-quality research is required to better understand the contribution and impact of using EBCD on a psychiatric ward.

Most studies within this review had different aims and objectives with variations in their design; however, they were predominately qualitative and descriptive in nature. There were a small number of quantitative studies that concluded that service user involvement improves clinical outcomes; however, this was limited to service user led research, rather than specifically the use of EBCD in either a health or mental health setting. One study looked at using EBCD in an adult mental health inpatient setting, and highlighted the benefits this approach may bring in this setting.

A number of key issues emerged from the findings of this review. There is growing agreement that the use of service user involvement is key in the design of health services (Department of Health, 2005). This points to an increasing awareness of the patients' experience; Darzi (2008) states that patient experience is seen as a key message in designing future services. However, there is also an acknowledgement that services are often designed around the needs of the staff rather than the patients (NHS England, 2013).

Examining the studies related to service user led research and participatory action research a number of commonalities emerge. There appears to be a consensus that involving service users in research improves the way that care is delivered and also improves the way that service users experience the delivery of that care. The evidence presented for this conclusion is largely based on qualitative feedback from service users' and there is a concern from a number of the studies that service users who feedback in this manner are a largely self-selecting group and do not present a wide representation; 'hard to reach' groups can easily be overlooked. There are also limited quantitative studies that empirically demonstrate any care improvement.

The greatest benefit discussed in the studies is that involving service users in research into healthcare provision increases the providers' awareness of the issues that are of a concern to service users. A number of the studies concluded that increased awareness

of issues that are pertinent to service users and therefore really matter to them and contributes to increased patient empowerment. However, this issue also appears for a number of studies to highlight the power imbalances that are within health care between service users and staff; an issue which is even more pronounced in mental health care.

The papers relating to the use of EBCD in a physical health care setting are largely descriptive in nature and describe the implementation of EBCD in a variety of healthcare settings; there is limited evidence that demonstrate an improvement in clinical outcomes. Tsianakas et al, (2015) describes a feasibility trial which supports the undertaking of an RCT to determine EBCD effectiveness in designing an intervention to support carers of patients about to receive chemotherapy. The studies that explore EBCD also reinforce the findings from the studies of service user led research and participatory action research, namely that using EBCD as a quality improvement process increases staff and providers awareness of the issues that are of a concern to service users. However, involving service users in healthcare research highlights the power imbalance between them and the staff. Nonetheless, the studies conclude that implementing EBCD in a health care setting is a positive way to bring all stakeholders together and allows for meaningful service user involvement; as a result of the EBCD process service user satisfaction in the delivery of health care is increased. However, a number of studies conclude that being involved in the EBCD process has different meanings to different stakeholders, with staff sometimes being reluctant participants.

There is limited evidence regarding the implementation of EBCD in a mental health setting. The conclusions from the small number of studies is that EBCD can be applied in such settings but that a number of adaptations are required due to the nature of mental health provision. The most important of these adaptations is that because of the vulnerable nature of mental health service users, more consideration is required to support them through the process.

2.8. Summary

As has been highlighted earlier, patients' experience of inpatient mental health services is not always positive; it is for precisely this reason that EBCD was selected as an intervention to try to improve the way that adult inpatient mental health services are delivered. EBCD does not just ask user groups to feedback suggested changes to healthcare but brings patients and professionals together throughout the change process to co-design services in partnership (Bate & Robert, 2006).

EBCD has been used in adult inpatient mental health services in one study, (Springham and Robert, 2015) the results of previous studies have indicated that using the experience of service users who receive health services could improve the way healthcare is delivered, leading to greater satisfaction for both patients and staff. However, although existing evidence points to an increase in satisfaction, there are not yet any robust studies indicating that EBCD actually improves patient outcomes. The studies highlighted in sections 2.5 and 2.6 in this chapter have used EBCD in a variety of healthcare settings; however, taken together there is still not strong empirical evidence to support an assertion that EBCD actually does improve patient experience and outcomes. Establishing the effectiveness of EBCD is, therefore, a valid area for further study.

Chapter 3

Experienced-based Co design

3.1. Introduction

This chapter describes the quality improvement approach that was implemented in the case study site where my research was conducted. It begins with a description of the approach – Experience-based Co design (EBCD) – as it has traditionally been described and implemented and then details the adaptations which were made to the approach by the service users who led the work locally.

The intervention studied in this research-based thesis is called Experience-based Co design (EBCD). EBCD was selected following a literature search and the rationale for its use has been provided earlier in this thesis (see section 2.8). EBCD is a user-focused design process with the goal of making user experience accessible to service designers in order to enable them to conceive of improving experiences as well as systems or processes. Experience in the context of health care services is defined by Bate and Robert (2006: 308) as “how well people understand [a service], how they feel about it while they are using it, how well it serves its purpose, and how well it fits into the context in which they are using it”.

Bate and Robert (2006) suggest that by identifying the key moments and places, or ‘touch points’ as the authors refer to them, where people come into contact with a service and where their subjective experience is shaped, it is possible to begin designing better experiences that improve a service pathway. The co design aspect of the EBCD intervention results from the patient group and the healthcare professionals working together to explore the ‘touch points’ and then subsequently identifying improvements and implementing those changes that redesign the service. For Bate and Robert (2006), co design suggests a partnership and shared leadership between health care staff and patients, with both sides being able to input their respective experiences and perspectives into the improvement project on equal terms.

3.2. EBCD six stage process

Robert et al (2015) describe EBCD as a six-stage process, which can take up to a year to implement.

1. Setting up the project
2. Gathering staff experiences through observation and in-depth interviews
3. Gathering patient and carer experiences through filmed narrative based interviews
4. Bringing staff, patients, and carers together to share their experiences of a service and identify their shared priorities for improvement, prompted by an edited 30 minute 'trigger film' of patient narratives
5. Small groups of patients and staff work on the identified priorities (typically 4-6) over three or four months
6. Celebration and review event.

This can be seen below in Figure 3-1.

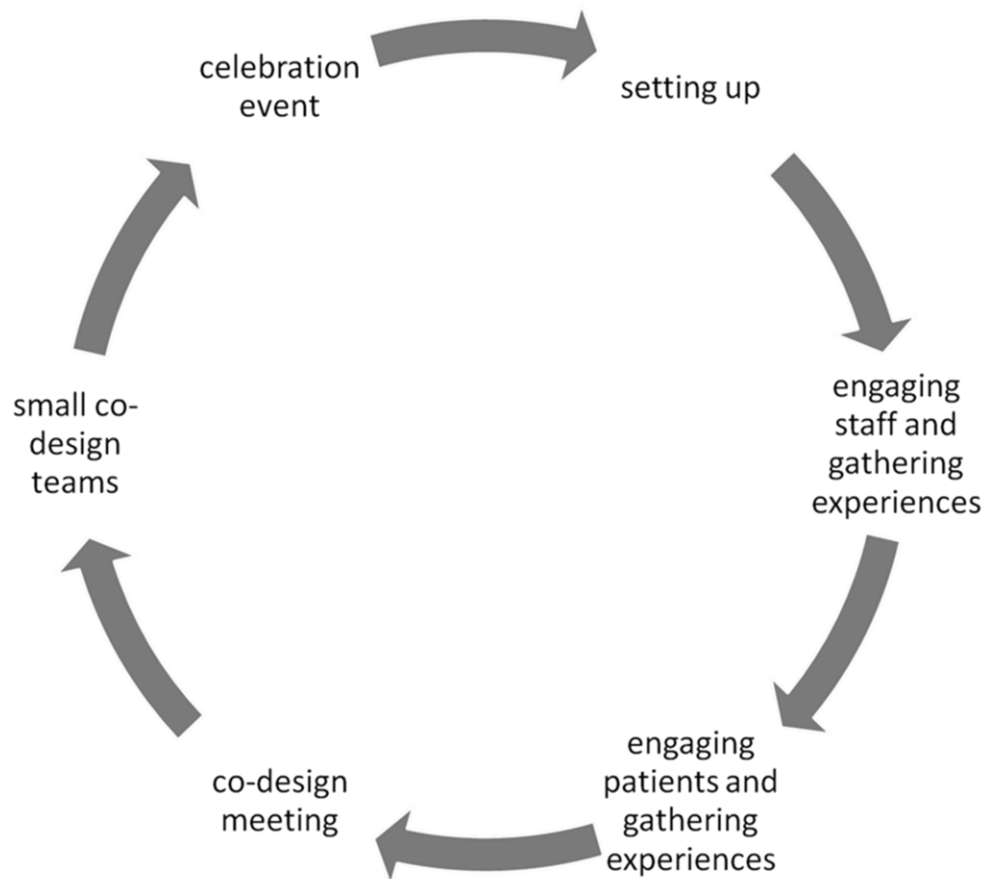


Figure 3-1 EB CD six stage process; Robert (2013).

3.2.1. Setting up the project

Establishing governance and project management arrangements is the first stage in the implementation of an EB CD process, (Robert, 2013), this overseeing project group will comprise of senior staff and also those responsible for the implementation of the

EBCD project. Key to this core group, according to Bate and Robert (2007) are the senior managers and clinicians in the proposed area for the EBCD project.

Liaising with senior staff:

In order for the EBCD approach to have the greatest chance of success, Bate and Robert (2007) suggest that it is vital that senior clinical staff and senior managers are approached and are on board with the process. This, for Bate and Robert (2007: 121) is in part so that the senior staff can “advise and encourage” other staff. The Kings Fund (2011) also identified the support of key staff in clinical areas as a key enabler to the success of the process.

3.2.2. Gathering staff experience through observation and in-depth interviews

Observation of work and healthcare delivery environment

Bate and Robert (2007: 88) suggest using the ethnographic method of non-participant observation as part of the process of engaging staff; they term this “organisational loitering”. This observation of the work environment allows an understanding of how and why things work, and to see how staff and patients go about their everyday activities. Non-participant observation has the advantage that it allows researchers to gain an understanding of an environment by observation and questioning, however a weakness of this method is that any observation is likely to be biased by the researcher own view point; it is, therefore, important that the researcher’s biases are considered (Silverman, 2010).

Staff interviews

As part of the engaging staff in the process of EBCD, Bate and Robert (2007) also recommend direct staff interviews of a range of clinical staff who work in the selected work area. The aim of the interviews is to gather concrete information from staff and to gain an understanding of their perception of their work environment. Whilst this is clearly a useful way to obtain data on how people understand and feel about their work environment, it can also be subject to researcher bias (Silverman, 2010).

Staff event

The anonymised results of these interviews and observations are then feedback to the staff group at a staff event. An outline of the stages of the EBCD process is then presented to staff. Following a discussion of the issues and themes emerging from the observational and interview data, the staff group then together select what it feels are

the most pertinent 'touch points' for service improvement and these 'touch points' are then taken to the service user group for their consideration and comment.

3.2.3. Gathering patient and carer experiences through filmed narrative based interviews

Engaging service users:

Service users and their carers are vital to the EBCD process and recruitment of them to the project can be undertaken in a number of ways: direct requests from clinical staff, posters asking for volunteers or approaching a pre-existing service user forum. Service users can then have the rationale of EBCD explained to them and subsequently they are given the opportunity to be interviewed about their recollections and reflections on receiving care in the chosen service. All service users and carers who are interviewed then view their interviews to decide if they are happy to share. Bate and Robert (2007) suggest video filming the interviews to help trigger and enhance the impact of staff and service users coming together to understand the service users experience. Robert et al (2015) expand on this notion and acknowledge that although filming patient stories takes time and is resource intensive, it does provide a convincing catalyst for change.

Videoing of service users

Petri (2011) tells us that filming patients requires complete respect for their confidentiality and privacy and must be centred on the patient's autonomy to give consent; it is vital that information is kept confidential and private. Petri (2011) suggests that anonymisation, such as distorting an image of a participant, should be offered to patients agreeing to be filmed even when they have given consent. Previous studies have used filming recording with mental health patients, (Kennedy and Yellowlees, 2003; McLaren et al, 1999); both studies reported high levels of user acceptance to the process. Although potentially problematic in terms of maintaining confidentiality, filming service users is highlighted by Bate and Robert (2007) as one of the most important aspects of the EBCD process, as it was the most effective and powerful way to impart people's experience, although audio recording can be offered if service users felt uncomfortable.

3.2.4. The 'joint event'

The two groups, service users and staff, are brought together and the service users' film is played to both groups together. This is the first time in the process that both groups are brought together to share their experiences of giving and receiving care.

The mixed group of staff and service users discuss the issues highlighted in the films and also considers the issues raised at the staff event and also the meetings with the service users, first as a whole group and then the large group splits into smaller groups with a combination of both staff and patients in each group. The groups reflect and decide what it feels are the key issues or 'touch points' in the experience. At the end of the event the whole group then decides the key 'touch points' that it wishes to work on; working co design teams are then formed to work on the selected 'touch points'.

3.2.5. The co design team Phase

The issues or 'touch points' that are highlighted following the 'joint event' are then used as the priorities for the staff and patient co design team to begin work on. Robert suggested that these joint co design groups are facilitated by a quality improvement lead from the participating healthcare organisation, as this allows for the patients to have an equal voice. Typically, four or five groups are set up for the different issues highlighted. The joint co design teams then meet together over a designated period of time to plan how to improve the service and then implement the improvements. Bate and Robert (2007) state that three months was an appropriate timescale for the completion of the work streams. The redesigns are then to be implemented by the joint staff and service user working groups.

3.2.6. Celebration and review event

After the three month period, the different co design groups then reconvene at an event to reflect on the work they have done, celebrate their successes and then plan for the next stage of the implementation of service improvement.

3.3. King's Fund EBCD Toolkit

In 2013, the King's Fund (King's Fund, 2013) developed a toolkit to assist and support people in undertaking an EBCD project. This toolkit provides a step-by-step guidance to undertake an EBCD project; it also provides a number of downloadable forms to assist in the project, such as template forms and letters to help in the EBCD project. The toolkit also included interviews with people who have undertaken EBCD projects, so provides useful advice about the practicalities of undertaking such a project. The King's fund toolkit will be utilised and followed in the implementation of this EBCD project.

3.4. Differences to EBCD process for this project

The EBCD project that is subject to this research differs from the traditional EBCD approach as described in the earlier part of this chapter, full details of these differences are now outlined. The biggest difference in this research is who undertakes the actual research, for this project the six stages of EBCD will be undertaken by a service user research group called 'Research Net'. Research Net were a pre-existing service user group who had previous involvement in quality improvement work in the healthcare trust selected for EBCD intervention, they also had previous experience of implementing an EBCD project. Research Net are a pre-existing group of service users who regularly meet to support each other and discuss mental health care and have as their goal, to improve care. Service Users from this pre-existing service user group will undertake the role of implementing the EBCD project, they will undertake the six stages of the EBCD intervention, outlined in section 3.2, they will liaise with senior staff, observe the work environment, interview staff, lead the staff event, interview and film the service users about their experience of receiving care, lead the joint staff and service user event and then lead the subsequent work streams.

Members of Research Net attended initial meetings with senior staff, the assistant director for mental health services in the ward's geographical area and also met with the ward manager of the ward selected for the project to plan the implementation of EBCD on the ward. The next stage was understanding the staff experience, and Research Net took control over this stage; they observed the working environment, sat in on handovers and ward rounds and then interviewed a selection of ward staff, from the consultant psychiatrist to a healthcare assistant.

Research Net then worked on how to present the observations and interviews to staff at the staff event, which they were fully involved in. The staff event was facilitated by a staff member of Research Net, who had had previous experience of undertaking an EBCD intervention, but the service user members of Research Net were also at the staff event, they planned the day and had placed themselves on each of the tables, so that there were two service user members of Research Net on each table, this is different to the traditional EBCD process, as service users are not usually involved at this stage.

Research Net devised a system where they had control over the project at all stages particularly around the filming, editing, consent and showing of the films. Service users from within Research Net tended to take part after seeing each other's films, and seeing that the focus of the films was on defining what good practice was. Service

users, who had experienced a range of conditions from anxiety and depression, borderline personality disorder and psychosis, were interviewed from within Research Net. The films both powerfully described the lived experience of mental health service use and the types of interventions which had made a difference to them on wards.

All aspects of Research Net undertaking the EBCD project required careful consideration and a great deal of preparation within Research Net, because people were anxious and at times scared, often this was the first time some people had been back on a psychiatric ward, since they were unwell. Research Net is a group that was built on strong solid support and being with others who had shared knowledge of mental health. Research Net believe the EBCD project could not have worked without taking place in an established service user group. As the group knew each other well, so have a good sense of when to challenge each other, withdraw, accept limitations and ask for help. The use of a service user forums for this design is a strength, Bowling (2009) states this is termed purposive sampling, where respondents are selected because of the have knowledge of the subject area, in this case their unique knowledge of how care is delivered on psychiatric wards.

The other major difference in this EBCD project is that Research Net will, as well as filming the service users' stories, will also be the service users narrating their stories on film. This is because of their previous experience of implementing an EBCD project, the service users they approached to be filmed, whilst keen to improve the care on a psychiatric ward, were reluctant to share their stories, in case they had to be admitted to the ward again. One service user described this as 'a trauma upon a trauma', studies show that recall of traumatic experience without care for emotional processing can itself add to trauma and can itself precipitate clinical disorders (Lillienfeld, 2007). For this reason of not traumatising service users, Research Net decided not to hold a service user event to gather service user experience, but to obtain service users experience from within the ranks of Research Net, so they would film their own experiences of being on a psychiatric ward and use these narratives to be shown at the joint event.

The joint event was facilitated by the same person that facilitated the staff event; the staff member of Research Net. As with the staff event, Research Net planned the event and provided support to each other before, during and after the event, part of this planning was deciding how many members of Research Net would sit at each table and then who would lead or facilitate each table, decisions were made prior to the event as to how the tables would be facilitated.

At the end of the joint event, the workstreams were decided and dates to meet were agreed, Research Net took the lead on this supported by the facilitator of the event and service user members subsequently led on the workstreams, both encouraging attendance and moving the project along.

3.5. Summary

This chapter has described a traditional EBCD QI intervention and has outlined the six stages that are used in an EBCD process. The chapter has then gone on to describe the differences to the traditional EBCD process that were undertaken for the purpose of this study, these differences are focused around the EBCD intervention being led by a service user group and the intervention being carried out in a mental health setting, both of which required adaptations to be made, as has been highlighted by the studies explored in Chapter 2, the literature review. The next chapter will state this studies' research aims and objectives and the subsequent chapter will describe the methodology to be undertaken in this study to meet the aims and objectives.

Chapter 4

Research Design

4.1. Introduction

Previous chapters have discussed the importance of service user involvement in the design of healthcare services and highlighted a quality improvement methodology called Experience-based Co-design (EBCD) as a way to improve services.

The following chapter sets out the philosophical framework and research methods underpinning the empirical study which was undertaken to explore the EBCD approach as applied in a particular acute mental health setting. It will begin the chapter by setting out the aims and objectives of the research to address this.

The overall aim of this thesis is to explore and evaluate the impact of a service-user led co-design intervention to improve service user and staff experiences on an adult acute psychiatric in-patient ward. The primary research question is whether a service-user led collaboration between staff and service users can improve experiences on an adult psychiatric in-patient ward.

4.2. Research objectives

In attempting to meet the aims of the study, specific research objectives were considered. The specific study objectives are to:

- prospectively study the implementation of a service-user led Experience-based Co design (EBCD) intervention on an adult psychiatric in-patient ward
- explore whether such a service-user led co design intervention can be successfully implemented in this setting
- measure the impact of the service-user led co design intervention by comparing the ward atmosphere before and after its implementation and identifying any changes
- explore the role and impact of the service-user led group in the implementation of EBCD.

4.3. Philosophical framework

This research project is a study of EBCD as it was implemented on an adult psychiatric ward. The study design was a multiple methods, process evaluation of EBCD as a

quality improvement intervention. An important feature of the intervention under study is that it was led by a local service-user group (Research Net).

The study draws on a realist philosophy, namely that evaluation of cultures and constructs needs to take into account the 'real'; the reality of those actually involved or those who experience the phenomena under evaluation and that the purpose of that evaluation is to change practice, policy and thinking (Pawson & Tilley, 1997). For Pawson and Tilley (1997) realism's strength is the emphasis it places on the explanation of what is being evaluated, leading to continuing development of the scientific knowledge surrounding the constructs under evaluation. This study is seeking to understand both whether EB CD has an impact on patient and staff experiences on a psychiatric ward and also why EB CD impacts on those experiences from the perspectives of those who took part.

There are often divisions between quantitative and qualitative research design but Ritchie and Lewis (2003) encourage pragmatism in researchers and suggest that quantitative and qualitative research methods should be seen as complementary strategies in a researcher's toolkit, rather than competing and contradictory. The rationale for using a multiple methods approach in this research project is that EB CD is an innovative intervention which is increasingly being used to improve the quality of healthcare services. In the previous chapter the literature review highlighted a report by Donetto et al (2014) that identified 59 EB CD projects which had been implemented in 6 countries to improve quality, and that the authors were aware of another 27 projects that were being planned. However, EB CD has rarely been used in psychiatric in-patient wards and consequently very little is known about its effectiveness. Due to this lack of knowledge, enquiries into the nature and impact of EB CD are exploratory; using non-participant observation and interviews will help develop a broader understanding of the pertinent issues which shape the impact of the intervention under study. As the implementation of EB CD in the acute mental health in-patients ward setting is a new area of research, the author anticipated that the use of a multiple methodology to examine the impact of EB CD will provide a more complete understanding of how and why it has impacted on staff and patient experiences. A multiple methodology for studying a research problem, particularly a new area of research, provides more evidence than solely relying on quantitative or qualitative research alone, (Creswell and Plano Clark, 2011).

The rationale for using multiple methods for the research design within this study came from the literature review. The review of the literature indicated that there was limited evidence of EBCD's applicability to a mental health setting; using qualitative and quantitative methods allowed for a greater understanding as to both EBCD's applicability to a mental health setting but also the nature and mechanisms of its impact. It was important to understand, firstly, whether staff and service users perception of the EBCD process converged or diverged from what the author observed and secondly to allow the opportunity for the quantitative results to demonstrate whether or not EBCD had any impact on service user and staff experiences on the ward.

The following section further discusses the rationale for using a multiple methods design and describes the data collection within this.

Multiple methodology research has become a common component of research within health services (O'Cathain et al 2010). The main purposes for combining methods in studies have been highlighted by O'Cathain (2010). These include:

- Complementarity – methods are used to address different aspects of the same question.
- Expansion – methods are used to address different questions.
- Development – one method is used to inform the development of another.
- Confirmation – the results of the two methods converge.

This study utilised multiple methods to address the need for complementarity and confirmation. Use of the WAS survey provided the evidence as to whether the EBCD intervention had an impact on the experience of staff and service users on an acute psychiatric ward, whereas the interview and observational data allowed staff and service users to articulate how they felt EBCD would impact on the experience of giving and receiving care on a psychiatric ward. The two data sources allowed the researcher to address different aspects of the same question in order to determine whether the results converge.

Within multiple methodology, a research problem is examined using different methods of data collection to gain a more complete picture (O'Cathain et al 2010). Both sets of data can then be analysed using a process known as 'triangulation'. Denzin (1978), first described and outlined how to triangulate research methods and described 4 types of triangulation including:

1. Data Triangulation – using a variety of sources within a study.
2. Investigator Triangulation – use of different researchers.

3. Theory Triangulation – use of multiple perspectives and theories to interpret results.
4. Methodological Triangulation – use of multiple methods to study a research question.

This study uses methodological triangulation through the use of the WAS survey, observational data and interviews. When the methods are integrated a process of interpretation takes place as the data from each method is initially analysed separately and the findings are then integrated (O’Cathain 2010). Each set of data on its own provides part of the story for the research question but together they contribute to a broader understanding of the research question (Farmer et al 2006). According to O’Cathain et al (2010), triangulation enables the findings to be explored for the following:

- Convergence – do the findings agree?
- Complementarity – do the findings offer complementary information on the same issue?
- Discrepancy – do the findings contradict each other?

4.4. The author’s role in the research project

The author has previously worked collaboratively with an art therapist to implement EBCD on a different ward in the same NHS trust in which this current evaluation of the EBCD process was carried out. In this previous project the author was involved in all aspects of the EBCD process, from the observation of the ward, the interviews with staff, the patient event and the subsequent filming of the patients’ stories. The author also jointly facilitated the staff event and the joint staff and patient event with the art therapist and was involved in the setting up of the joint patient and staff work streams to co-design specific aspects of care.

Given this previous involvement - both with EBCD and the same NHS Trust - it is important to clarify the author’s role in the current research study. For the purpose of this research the author explored and evaluated the impact of the EBCD process rather than implement it; the implementation of EBCD was carried out by a service-user group (Research Net). Research Net’s remit (see below) is the audit, evaluation and improvement of mental health care in the NHS trust in which the study is to be carried out. Research Net carried out all aspects of the EBCD implementation process, following the detailed staged process set out in the freely available, online EBCD toolkit, on The King’s Fund website, www.kingsfund.org.uk/projects/ebcd (Accessed 2013), as described in Chapter 3. Prior to the EBCD intervention being implemented, the author worked closely with Research Net, to share his experience in

implementation of the previous EBCD intervention and to act as a support and guide to the Research Net group, acting as a type of 'knowledge broker' (Lomas, 2006). The research design section below describes the methods used by the author throughout the research process.

4.5. Research Net

Research Net began in 2010 in one geographical area of an urban Mental Health Trust and is now a network of locality based research groups operating within that Mental Health Trust which is the setting for this study; within each research group service-users, carers and staff meet together on a weekly basis (Springham et al, 2011). Research Net is a service user-led group that is co facilitated with one or two members of staff, the staff assist and enable the service users to undertake the research activity that they have identified. The service users select the clinical areas they wish to undertake a quality improvement (QI) project on and the QI methodology that they will follow. They have completed a number of QI projects within the trust in a number of care areas, EBCD is a methodology that they have used in 6 QI projects, but they have also led on service user experience audits in all 8 of the trusts wards, and were also leading on similar service user experience audits in the 6 community mental health teams. There are currently five such groups across the trust each comprising approximately 12 voluntary members with more in preparation. The NHS Trust's commitment to facilitating weekly meetings has allowed immersive collegial relationships to develop between service-users and the provider, who otherwise are often segregated. Whilst Research Net groups are convened by frontline clinical staff, they have a strong relationship with senior managers. Research Net has made regular presentations to the executive board and sits on the patient experience board on the work they have undertaken. More importantly, weekly Research Net groups also provide a space for senior managers, from the CEO down, to regularly visit to take part in frank discussions about the reality of frontline clinical experience. These meetings, with their strange mix of seriousness and humour, seem to fulfil a useful role not facilitated by any other forum in the Trust. The direction of Research Net activity is negotiated in a flat hierarchy by these three populations (managers, frontline staff, service-users) talking together in this 'space'.

Prior to implementing EBCD, members of Research Net had already been used to working with both their and others lived experience, turning their personal stories into structured research (which increasingly became a fundamental part of their recovery). One of this group's earliest projects was undertaken by two members of Research Net, both art therapists, who undertook heuristic research (Moustakas, 1999) into acute

mental health, to explore the lived experience of the researchers in both giving and receiving care in adult mental health care. One of the therapists had previously had an admission to one of the Trusts acute mental health wards where the other therapist delivered art therapy. The research aimed to examine what could be learnt from the experience of someone admitted to one of the wards' in order to improve the art therapy delivered by the other therapist. This resulted in user-valued descriptions of the issues involved and specified what good clinical practice is, and also highlighted an approach which (unwittingly at the time) matched some aspects of EBCD quite closely. Crucially, the research process highlighted not only how challenging it is to recall and communicate lived experiences of severe mental health difficulties but also that investigation into people's lived experience has the potential to be re-traumatising if not conducted carefully. A supportive and effective methodology for structuring recalled experience through stepped audio-recorded interviews was developed, from which themes were extracted. The resulting paper "On learning from being the inpatient", (Woods & Springham, 2011) was published and presented to both the Trust research conference and executive board. Following this there began a focus on acute mental health care in the Trust, as an area of concern which has consistently been reiterated by all Research Net groups.

4.5.1. Research Nets role in the EBCD intervention

As described in Chapter 3, section 3.4, Research Net led on the EBCD intervention, and carried out the implementation of the EBCD process, following the guidance given in the EBCD toolkit (The Kings Fund, 2013), together with support from both the author and the art therapist, as based on their previous experience of implementing an EBCD process. As highlighted in section 3.4, this took the form of Research Net liaising with senior staff, both managerial and clinical staff responsible for the ward prior to the project beginning, they negotiated and planned with the ward manager how the observations and interviews would be carried out and they themselves undertook the observations of the psychiatric ward, then identified and interviewed a cross section of staff from the ward to elicit their experiences of working there and what they thought were the emotional touch points for service users receiving care on their ward.

Following the observations and interviews with staff, Research Net were then fully involved in the staff event. The event was facilitated by the art therapist, who was a staff member of another Research Net group in the mental health trust, but he had worked with Research Net to plan the day, together they organised how the event would run and how the information from the interviews and observations would be feedback to the ward staff. They also planned how the room would be set up and which

members of Research Net would sit on which table and what their role would be on the day.

As was highlighted in section 3.4, Research Net did not hold a service user event to gather service user feedback, as previous experience had shown them the traumatising nature of filming mental health service users' narratives. Research Net then identified service users from within their own ranks to be interviewed and filmed about their experience of receiving care on the psychiatric ward, as some of the members of Research Net had been involved in a previous EBCD project, they decided to set up a support group to support their colleagues through the process. The Research Net group which undertook the EBCD project were in the unique position of containing some members of the group who had been filmed in the previous EBCD intervention carried out by the author and the art therapist, so were ideally placed to understand the potential for mental health patients to be re-traumatised by going through their lived experience. Members of Research Net also filmed and edited all the service user narratives and together with the art therapist decided how their narratives would be shown at the joint event.

The facilitation of the joint event was undertaken by the art therapist, as with the staff event Research Net met with the facilitator and together they planned the day, how the day would run, how the information would be presented to the staff, which member of Research Net would sit on which table and how they would obtain feedback to the films of service user experience. They also decided how they would ensure that the workstreams were identified and planned at the joint event and who from Research Net would be involved in the works streams.

4.6. Study setting

The EBCD intervention was carried out on one specific ward in the Trust where the author had previously worked; random assignment to the intervention was not feasible. The Trust has eight acute admission wards, each of which is twenty bedded which are sited in three different geographical locations; three wards each in two locations and two wards in the final location. The patient population in each of the wards is similar in terms of gender, age and type of mental illness.

The ward in which EBCD was implemented has 20 beds and 24 members of staff; it is sited in the geographical location that has two wards. The ward was selected by the Assistant Director of Mental Health Services as the venue for Research Net to undertake the implementation of EBCD; no rationale was provided to the author or to Research Net as to why this ward was selected. The study ward is therefore a

convenience sample in accordance with Petrie and Sabine's (2009) definition. A convenience sample has the advantage that participants are easier to recruit and are likely to respond; however the results may be less transferrable to other populations as the study population does not represent a truly random group of respondents (Bowling, 2009).

The ward was a locked mixed gender ward and supports both formal and informal patients, formal patients are those detained under a section of the Mental Health Act for compulsory assessment or treatment, informal patients are those who are on the ward voluntarily and can therefore leave when they wish. The patients on the ward cover a wide diagnostic range, including depression, anxiety, psychosis, bi-polar disorder and personality disorder. The age range of the ward for patients is between 18 and 65 years of age.

4.7. Pre-intervention 'knowledge broker'

As mentioned above, the author had previously been involved in an implementation of EBCD in the same NHS trust where this study took place; this previous knowledge placed the author in the unique position of being able to work with Research Net to offer support to them. A close and trusting relationship with the Research Net group was important as the research was focused on the observation and evaluation of a quality improvement intervention that they, Research Net, were undertaking.

Research Net met on a weekly basis, details of these meeting are in Chapter 5, in section 5.2.1. The author attended these meetings on a monthly basis to develop a relationship with the group, during the time the author would share knowledge of how the previous EBCD implementation occurred, offering advice and support relating to the process and pitfalls or likely issues. This time spent acting as a 'knowledge broker' engendered the building of trust between Research Net and the author which was considered to be vital in allowing the author to effectively observe and evaluate the implementation of EBCD.

4.8. Overall research design

This study was undertaken using a multiple methods approach incorporating (a) qualitative, semi-structured interviews with members of Research Net and staff as well as non-participant observations of the key events in the EBCD process and (b) a quantitative pre-post evaluation measuring patient experience of receiving care on a psychiatric ward and staff experience of giving care on the same ward (using a validated survey instrument described below).

The research into the implementation and evaluation of the EBCD project was undertaken in 7 phases:

1. Baseline evaluation (pre-intervention survey)
2. Observation of the EBCD staff event
3. Interviews with people involved in the EBCD staff event
4. Observation of the EBCD joint patient & staff event
5. Interviews with people involved in the EBCD joint patient & staff event
6. Post intervention survey
7. Data Analysis

Each of these phases is now discussed – in turn – below.

4.8.1. Phase 1 – Baseline evaluation (pre-intervention survey)

Subjective patient experience of receiving care has generally been measured through patient satisfaction with services (Picker Institute Europe, 2004). The impact that the treatment environment has on patient outcomes has been acknowledged in several studies, (Timko & Moos, 1998; Smith et al, 1996; Middelboe et al, 2001, Rossberg & Friis, 2004)). For staff, a poor working environment reduces job satisfaction leading to stress and burnout (Gulliver et al, 2003). Roosberg and Friis (2004) noted that the ward environment can be experienced differently by different groups on a ward, suggesting that staff and patients can ‘live in different worlds’. To be able to get an understanding of the differences between these two groups’ perception of the ward environment, it is important to field a survey tool that can demonstrate any differences, enabling greater understanding of how each groups’ perception impacts on the care given and staffs ability to give care.

The Ward Atmosphere Scale (WAS) is a survey tool specifically designed to rate psychiatric inpatient experience and was designed to be completed by both staff and patients. The WAS was developed by Rudolph Moos (Moos, 1974; 1996) as a scale to measure the treatment environment and is considered the most widely used instrument of its kind (Moos, 1996; Rossberg & Friis, 2004). It has been in use since the mid-1970’s; its normative data was based on 160 Mental Health In-patient units in the USA and subsequently normed on a large sample of UK wards, (Moos, 1996; Rossberg & Friis, 2003). The scale is a 100-item questionnaire, set out in a true/false format (see Appendix 4). The items map onto 10 sub scales, each of which falls into one of three dimensions of the treatment environment, relationship dimension; personal growth dimension and system maintenance dimension:

1. The Relationship dimension, which includes the Involvement and the Support & Spontaneity sub-scales.

2. The Personal Growth dimension, which includes the Autonomy, Practical Orientation, Personal Problem Orientation and Anger & Aggression sub-scales.
3. The system Maintenance dimension, which includes the Order & Organisation, Programme Clarity and Staff Control sub-scales.

The detail of each of the 10 sub scales is described in the results chapter, in section 5.7.1.

The WAS allows each service user and each member of staff who completes the questionnaire to give their opinion about the usual behaviours and expectations in a ward. The scales have been used to measure a collective perception of the sub scales. This is achieved by calculating the mean scores of a group of individuals rating the same sub scale. Such mean scores are much less sensitive to individual bias, and can be regarded as measures of the ward atmosphere, (Friis, 2007). Service users and staff are given the same forms. Data is presented initially as a raw score and then converted to a standard score, which allow comparisons between the means of service user and staff score, (Moos, 1996).

One month prior to Research Net beginning the EBCD project the WAS survey tool was fielded in order to gain a baseline evaluation of patient and staff experience of the ward selected. All 20 patients that were on the ward at the time were surveyed; there would only ever be a maximum of 20 patients on the ward at anyone one time. All 24 staff who were working on the ward at the same time were approached to complete the WAS survey. Staff and patients were not asked to sign a consent form as the survey is anonymous and completion of the survey was deemed as providing implied consent.

The researcher had visited the ward and spoken with the ward manager about the WAS survey tool and the rationale for its selection as the tool to obtain staff and patient experience of the ward. The ward manager spoke with the ward nursing team at a business meeting, explained the rationale for the survey and handed out the survey to all 24 staff on the ward; the ward staffing complement comprises of 1 ward manager, 2 charge nurses, 10 staff nurses, 8 health care assistants, 1 occupational therapist and 1 psychologist. Staff were given a week to complete the survey, reminders were verbal and took the form of verbal reminders in the handovers between shifts, during the week selected. The completed surveys were returned to the ward manager. Out of the 24 surveys distributed to staff, 14 (70%) were completed.

The ward manager also spoke to all 20 patients on the ward at their community meeting, explained the rationale for the survey and handed out the survey to all 20 patients who were on the ward at that time; no patient was excluded from the survey.

The ward manager asked the patients to return the surveys to him, reminders to the patients were from the ward manager and the patients were also allowed the same week to complete the survey. Out of the 20 patients on the ward, 14 patients (70%) completed the survey.

The ward manager then collated all the completed surveys and contacted the researcher to collect the surveys. The survey response was anonymous, and so demographics were not available.

4.8.2. Phase 2 – Observation of the EBCD Staff Event

Research Net commenced their work by undertaking observations of the ward and interviewing key members of staff in order to gain an insight into the working environment and how care is delivered.

The next key phase of the research study involved the researcher observing what Bate and Robert (2007) describe as part of the development phase: the staff event. The staff event is where the anonymous results of the interviews and observations conducted by Research Net were fed back to the staff group. The event was facilitated by the art therapist who had led the previous EBCD implementation in the same Trust. EBCD was described to the staff by the art therapist to remind them of the place and contribution of the staff event in the whole process. Following discussion of the findings from the observations and interviews conducted by Research Net, the staff group then together selected what it felt were the most pertinent 'touch points'; these 'touch points' were then taken to the service user group for their consideration and comment.

The researcher was a participant observer of this staff event in order to gain a greater understanding of 'how' the implementation of EBCD works and to help identify any relevant 'mechanisms and context' (Pawson & Tilley, 1997). Drawing on features of an ethnographic approach (Hammersley, 1998) this aspect of the fieldwork included the following features:

- People's behaviour was studied in everyday contexts
- Data was gathered from a range of sources
- The approach to data collection was unstructured
- The focus was on a single case study
- Analysis of data involved interpretation of meanings.

Prior to the event the researcher had spoken with key members of staff from the ward; the consultant psychiatrist, the ward manager and the consultant psychologist and the director responsible for the overall management of the service, to obtain permission to

attend and observe the event. Before the staff event commenced, the researcher addressed the audience and explained his attendance and distributed staff information leaflets which explained that all notes taken about the event would be anonymous. The researcher then clarified that he had permission to observe the event.

Observation of the event took the following form. The researcher arrived at the staff event prior to anyone else, noted the physical environment, noted the arrival of the staff to the event and noted the structure of the event and the agenda for the day. Whilst the event was underway, the researcher sat at the back of the room and observed and noted the discussions, who said or did not say anything, the reactions to conversation and his own reflections as to what was happening. If there were any breaks - coffee/tea and lunch - the researcher spent this time engaged with the participants of the event - the staff, Research Net and the art therapist - and asked for their reflections on the event. The researcher remained at the event until the last person left. Observational notes of the event contained a description of the content of the various components of the event, combined with the author's reflection on each particular component (see Appendix 5).

During the staff event, the author timed all aspects of the event, this was to evaluate how much time was spent adhering to EBCD toolkit, as presented by the King's Fund (The King's Fund, 2013), as fidelity to the EBCD model was important to understand EBCD's applicability to a mental health setting. Timings were also taken of what the author perceived as the staff and service users at the staff event were working together in co-design. This data will be presented in the results chapter and will be shown as a percentage of the overall time of the event.

During the staff event the researcher approached staff, Research Net and the facilitator to recruit them to be interviewed about their experience in participating in the EBCD process (see next phase below). The researcher recruited a cross section of the staff: the ward manager, two qualified nursing staff and one healthcare assistant. The researcher recruited four members of Research Net as well as the art therapist who had facilitated the event.

4.8.3. Phase 3 - Interviews of staff & Research Net

The interview process followed a semi-structured questioning format, which can be seen in Appendices 6 to 10, allowing the researcher to be able to gather from interviewees both how they felt about EBCD as an intervention and how they experienced the process. Silverman (2010) tells us that interviews are often used to gather respondents' perceptions to an experience; however, Gubrium and Holstein

(2002) warn that people may attach more than a single meaning to a situation or activity and that these emerge when they speak to each other or the researcher. Silverman (2010) states that using interviews to elicit perceptions is appropriate but that the researcher needs to be clear about what they are trying to get from the interview. For the purpose of this research the interviews were treated as a means of accessing individual participant's experience of EBCD, rather than a means to understand the narrative of multiple meanings of the situation.

As the researcher interviewed staff from the ward, Research Net as well as the facilitator (the art therapist) it was important that there were different questions depending on the role that each of the individuals played in the intervention process. All interviews were anonymous, and all interviewees were given participant information leaflets and asked to sign a consent form. All interviews were transcribed and anonymised, in preparation for analysis.

Confidentiality

All interview data were anonymised and interview participants were given pseudonyms within transcripts and all identifiable participant information remained confidential. The researcher, at all times, complied with good clinical practice guidelines in regard to data protection.

Data security

Interview participants were informed that the digital recordings of their interviews would be stored as encrypted files, as agreed with Research Ethics Committee, (REC), participants were also informed that data would be stored for a period of five years and then destroyed. Signed consent forms were stored separately from the data in a locked cabinet and secure office.

Each individual interviewee was allocated a unique pseudonym. These pseudonyms were stored separately from the consent forms and data and were destroyed after the data was analysed, as they were not needed after this point.

Interview with the Ward Manager

The ward manager is a key figure in seniority of the ward; from the researcher's experience with the previous implementation of EBCD, the ward manager is pivotal to the success or failure of an EBCD intervention. The researcher was seeking to gain an understanding of how the ward manager felt about the EBCD process and how they thought their ward felt about EBCD. The researcher asked the ward manager to provide a timeline of how and when the EBCD intervention came to be on their ward.

As the EBCD intervention was led by Research Net - which amongst its members had former patients from the ward - it was important to gain an understanding of how this felt from the point of view of the ward manager. The interview schedule for the ward manager is provided in Appendix 6 but the interview also covered how the process felt to the ward manager, concerns and expectations he had and explored his awareness of EBCD.

Interviews with staff members

The staff of the ward are clearly a key element in the EBCD process, their involvement and participation in the process is vital to successful implementation of the EBCD intervention. The questions for the staff sought to gain an awareness of the staff's understanding of the EBCD process. The interview schedule for the interview of the staff is provided in appendix 7 but the broad themes covered their awareness of EBCD, how it felt for them to participate and any anxieties or concerns that they had.

Interviews with Research Net

Research Net, as the service-user group, were the pivotal group for the successful implementation of the EBCD intervention. One key feature of their involvement in the process is that all of the members had experienced care on a psychiatric ward providing an understanding of how such wards feel from a patient perspective. The interview schedule for members of Research Net is provided in appendix 8, however the broad themes included Research net's experience of carrying out the observations and interviews, how it felt going back onto psychiatric ward, and their experience of the staff event.

Interview with facilitator (art therapist)

As the facilitator had previously led on EBCD intervention with the researcher in the same Trust, the questions for the facilitator sought to gain his reflections on how the two projects compared and how the event felt from his perspective as the facilitator. In the previous EBCD intervention, the researcher and current facilitator had undertaken the observations and the interviews, whereas in this intervention it was Research Net (former service users) who undertook the intervention. The researcher also wanted to gain an understanding of the facilitator's reflections on EBCD as undertaken in a mental health setting and how the facilitator felt this was different if at all to a physical health setting. The interview schedule can be found in appendix 9 but the broad themes that were covered included asking about his reflection of the staff event he facilitated and asking him to compare it to his previous experience of implementing

EBCD, as well as his reflections on the service-user group, Research net, leading the implementation of the intervention.

4.8.4. Phase 4 - Observing the Staff & Service User Event

The joint event is when the two groups, service users and staff, are brought together and the service-users' film is shown to both groups together. This is the first time in the process that both groups are brought together to share their experiences of giving and receiving care. Issues raised by the film are then discussed, first as a whole group and then in smaller groups with a combination of both staff and patients. The groups reflected and decided what it felt were the key issues or 'touch points' in the experience. At the end of the event the whole group then decided the key 'touch points' that it wished to work on together to improve; working groups were then formed to work on the selected 'touch points'. This joint event, like the staff event, was facilitated by the art therapist and Research Net.

The researcher observed this part of the EBCD process and followed the same participant observation process that was followed for the staff event (see above in section 4.8.2). The researcher was at the joint event between 08:15 and 13:30 to observe it.

The author timed all aspects of the joint event, as with the staff event to ascertain how much time was spent adhering to the EBCD toolkit (The King's Fund, 2013). This was to ascertain whether or not there was fidelity to the EBCD model, to provide an understanding of EBCD applicability to a mental health setting, timings were also taken of the authors percentage of the amount of time staff and service users spent in co-design at the event. Both timings will be presented in the results chapter, as a percentage of the overall time of the event.

Examples of observation notes taken by the researcher at the joint staff and patient event can be found in appendix 10. During the joint event, the author approached participants at the event, both staff, patients, Research Net and the facilitator to recruit them to be interviewed about their experience of being involved in the EBCD process.

4.8.5. Phase 5 – Interviews with people involved in the joint patient and staff event

Following the joint patient and staff event the author interviewed participants approached at that event. The interview process followed that which was for the interviews following the staff event (see above) including a semi-structured format

focusing on how participants felt about the EBCD intervention and how they experienced the process.

The author again interviewed staff from the ward, members of Research Net who were involved in the EBCD process and were filmed about their experience of receiving care on the ward, research net and the facilitator, it was important that there were different questions depending on the role that each of the individuals played in the intervention process. All interviews were anonymous, and all interviewees were given participant information leaflets and were asked to sign a consent form. All interviews were transcribed and anonymised, in preparation for analysis.

Interview with the Ward Manger

The interview schedule can be found in appendix 11, however the broad themes covered were what were the manager's expectations and anxieties, how he felt about having previous patients of the ward being involved, and what he thought of the films.

Interviews with staff members

The interview schedule for the staff can be found in appendix 12, however the broad themes for the staff covered how they found the event, what were their expectations and anxieties prior to the event, how did it feel working alongside patients they had nursed and finally how they found the films.

Interviews with Research Net

The interview schedule can be found in appendix 13, however the broad themes covered were how they found the event, what were there expectations and anxieties prior to the event, what was their experience of making and showing the films, what was their experience of the staffs' reactions to the films.

Interview with facilitator

The interview schedule for the facilitator can be found in appendix 14, but the broad themes covered were what were your expectations and anxieties before the joint event, what was experience of the joint event, what were strengths and weaknesses of using Research net as the patient group and finally are there any differences in implementing EBCD in a mental health setting.

4.8.6. Post intervention survey

In order to establish if any change has taken place in terms of the chosen variables being measured, it is vital that post intervention and pre-intervention results are

compared and that a sufficient time period has elapsed, (Bowling, 2009). This will vary according to what is being detected but in the case of EBCD Bate and Robert (2007) identified that staff and service user groups took up to three months to complete their co-design work streams; therefore, in order to detect any impact the co-design work streams may have on service user experience the author decided the second survey would be taken six months post the joint service user and staff event.

The selection of the staff and patients to completion the post intervention WAS scale and how the surveys were handed out, reminders sent and how they were collected followed the same process as the pre-intervention survey, as outlined in section 4.6.1. The ward manager spoke to the staff and the patients in the appropriate meeting; he gave out the surveys, gave everyone a week to complete the survey, and reminded them about it verbally on a shift by shift basis and collected the surveys in. Out of the 20 potential patients to complete the survey, 15 (75%) did and out of the potential 24 staff available to complete the survey, 14 (70%) did.

The post intervention evaluation phase was carried out on the same ward that the intervention of EBCD was selected to be carried out and the ward that the baseline intervention evaluation had been carried out on.

4.8.7. Data analysis

Quantitative data analysis

The quantitative measure of the WAS survey - pre and post intervention - was compared using a statistical analysis test to ascertain the impact of the EBCD intervention on ward environment. Advice was sought from a statistician for data analysis; this began with descriptive analysis and then moved onto comparative analysis.

To establish the most appropriate statistical method of analysis, it is vital to understand the type and level of data collected. Petrie and Sabine (2009) state that data comes from observations on variables and the resulting data will be one of two types, categorical or numerical and that both these types have two further subdivisions. Numerical data is data that takes a numerical value and is either nominal or ordinal, whereas categorical is when data can only belong to a number of distinct categories and sub divides into either discrete or continuous data.

In the case of this study, the type of data generated by the WAS rated scale of experience is categorical and because the data is ordered according to experience, i.e. whether the experience is good, bad etc., the sub set of data is categorical. The

analysis of the results was done using a t-test for unrelated data. The t-test is one of the most common parametric analyses used to see if there are any significant differences between the statistical measures of two samples; in this case the data at the beginning and then at the end of the study (Cohen, 1977). Coolican (1995) states that there are three assumptions that underline the use of a parametric test:

1. The level of measurement must be at least interval
2. The sample data is drawn from a normally distributed population
3. The variance of the two samples is not statistically different

These assumptions all apply in this case; therefore, the t-test was used as it is about a number of procedures that are concerned with comparing two averages. The t-test is also useful to researchers as it uses the standard deviation of the sample to estimate the standard error of the sampling distribution; this means that the actual calculation is relatively straightforward (Burns and Grove, 1997).

Data analysis of 10 sub-scale group mean scores were compared pre and post-intervention in service users and staff using an independent two group's t-test. Mean and standard deviation pre and post-intervention have been presented for each sub-scale, the pre and post mean difference and 95% confidence interval and p-value from the t-test (probability > t-value). An equality of variance test was performed prior to the t-test to determine whether Satterthwaite's correction was required if the variances were not equal. A total of ten sub-scales were compared. To establish whether the difference pre and post-intervention was due to chance or not the probability of exceeding the t-value was set to 0.05 or smaller (5% level of significance). To account for multiple testing (10 tests) this was further reduced by a magnitude of 10 to 0.005.

Qualitative data analysis

The qualitative data (observational notes of the staff event and the joint staff and patient event (Appendices 2 & 7) and the interview transcripts) were then analysed using thematic analysis. The observational field notes (Appendices 2 & 7) and the interview transcripts were coded, and the codes were then used to identify themes. These themes were then used to explore the 'how' and 'what' of the experience of the EBCD intervention from each groups' perspective. Examples of coding for the observational field notes can be found in appendix 15 and examples of coding for the interview transcripts can be found in appendix 16.

Thematic analysis was the method chosen in this study for analysing the qualitative data. Thematic analysis is a widely used qualitative analytic method, (Braun & Clark, 2006). Thematic analysis is a method for identifying, analysing and reporting patterns

or themes with data. It organises and describes data, but more than this, it interprets various aspects of the research topic (Boyatzis, 1998).

One of the key aims of this study was to explore the perspectives of staff and service users into the use of EBCD as a QI methodology, led by a service user group in a mental health setting and to determine whether EBCD could be used in a mental health setting and how did it feel for both staff and service users. Thematic analysis is a method of managing data that allows the comparison of themes across groups, this was important for this study, given the specific sampling of staff and service users. This method therefore enabled the researcher to examine data within and between the two groups of staff and service users.

Thematic analysis consists of six stages; the application of these stages in the current study is outlined in Table 4-1.

Table 4-1 Stages of thematic analysis

Stage	Activity	Application
One	Familiarising yourself with your data	Listened to interviews and read all 18 interview transcripts and observational field notes, making notes and analytic comments and topics of interest. The list of topics was checked against the interview topic guide and stated research objectives
Two	Generating initial codes	Initial codes were generated manually from all 18 interview transcripts and observational field notes Developed an initial framework that produced a list of 326 codes, which were generated from the interview topic guide This process was all done manually to manage the data See appendix 17 for example
Three	Searching for themes	Went through list of codes and sorted them into potential themes. Sorted codes into parent and grandparent codes that formed the main themes or sub-themes. See appendix 18 for example
Four	Reviewing themes	Went through each interview and assigned textual data to each theme Thematic sets were then created for theme, whole data set for each theme clustered together.

		Also data reviewed to determine if any additional themes were needed. There were none. All interviews checked to ensure there were no data that had not been captured and themed, all data had been captured.
Five	Defining and naming themes	Created an overall narrative for themes. Themes identified, named and described.
Six	Producing the report	Report written up and is presented in the results chapter

4.8.8. Integration of qualitative and quantitative data

Integration of qualitative and quantitative data is key to a multiple methods research and is defined as the process of linking qualitative and quantitative findings in the course of data analysis (Bryman 2007). The integration of the data can take place at any stage of the research process from formulation of the research question to analysis of the data (O’Cathain et al 2010). If integration did not happen, the knowledge gained from a multiple methods study is the same as an independent quantitative and qualitative study.

As discussed earlier in this chapter, analysis of both types of data sets involves a process of triangulation. Within this study triangulation was used to examine the impact that a service user led EBCD intervention had on the experiences of staff and service users of the acute psychiatric ward where the intervention took place. The study data was analysed to explore whether findings from the WAS questionnaire reflected those within the qualitative interview data where further detail was obtained. Bringing together the data revealed a greater depth of understanding regarding the issues and experiences of staff and service users. Aspects of the staff’ and service users’ experience of the EBCD intervention were briefly explored in phase 3 and were further explored with staff and service users in phase 5. Within this the quantitative data was able to highlight the impact that staff and service and users felt that EBCD had on the experience of delivering and receiving care on an acute psychiatric ward, e.g. will EBCD make a difference to the experience of staff service users on the ward. The qualitative data was able to further explore this with both staff and service users as well as gaining insight directly from service users who led the EBCD intervention. As described by O’Cathain et al (2010) the data can then be explored for convergence, complementarity and discrepancy, which will be undertaken in Chapter 6.

The goal of data analysis was to provide a detailed understanding of how a multiple methods approach allowed a broad, rich and in-depth understanding of how the

contribution of a service user led EBCD QI intervention had on the experience of staff and service users on an acute psychiatric ward.

4.9. Ethical Considerations

The study was submitted for ethical approval via the online Independent Research Application Service (IRAS). The title originally submitted via the IRAS online service to the East of England and Norfolk NRES committee was 'Exploring patient and staff experience of implementing experience based codesign to promote patient centred improvement in a community mental health team' (IRAS project ID: 144038). The location for the implementation of EBCD was originally a Community Mental Health Team (CMHT) as that was where Research Net had initially planned to implement the approach.

The Research Ethics Committee reviewed the application at a meeting which the researcher attended by telephone. The study was given a provisional opinion by the committee of a favourable ethical opinion, subject to receiving a complete response to the request for further information set out below. The authority to consider the researcher's responses and to confirm the Committee's final opinion was delegated to the Chair (REC reference: 14/EE/1084).

The further information and clarification that was required was to make changes to the participant information sheet in the following ways:

- To ensure that it was clear what process would be followed, should there be a disclosure of bad practice or any safeguarding issues during the interviews.
- Include details of where a participant would be signposted should they experience any distress following the interviews.
- Include details of how long the audio tapes will be stored for and how they will be disposed of.
- Include details of which COPES questionnaire is being used and how it fits in to this study.
- Remove any reference to friends and family taking part in the study.
- Proof read the PIS for staff, as in places, this appears to have been designed for patients.
- Ensure that it is clear that this process is part of the wider EBCD process.

The committee also asked that the study choose either interviews or focus groups as the format for gathering information and to ensure this is consistently followed throughout the study (as both methods had been suggested initially).

The further information was considered on behalf of the Committee by the Chair and favourable ethical opinion for the research was granted (subject to the condition of management permission or approval being obtained from the host organisation prior to the start of the study at the site concerned).

However, in October 2014, Research Net informed the author that the location for the implementation of EBCD was to change, the rationale was that Research Net were finding it difficult to engage with the CMHT. With the support of the director of services, Research Net identified a psychiatric adult acute inpatient ward within which to conduct EBCD. In discussions with the ethics committee, it was confirmed that this would be a substantial amendment to the study and appropriate documentation supporting the reasons for the amendment would be required before favourable opinion would be given. The substantial amendment documentation was submitted to the NRES committee clearly explaining the reasons for the change in the study setting.

Given the change in setting the study switched to a more appropriate survey instrument: the Ward Atmosphere Scale, (Moos, 1996). The title of the study was changed to 'Exploring patient and staff experience of implementing Experience based co-design to promote patient centred improvement in an acute mental health ward'. The committee gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

4.10. Summary

This chapter has described the research design and methods used within this multiple methods study, outlining the rationale for key methodological decisions for the study of EBCD as led by a service-user group called Research Net on a psychiatric acute admission ward. This chapter has described the research process for this study, the stages of research that are linked with the stages of the EBCD process. Quantitative evaluation in the form of the WAS survey was outlined to take place pre and post the EBCD intervention to ascertain EBCD's impact on the ward and qualitative observation and interviews to provide an understanding of EBCD applicability to a mental health setting and the experience of service users and staff in being involved in an EBCD project. The results from this research design, both the quantitative and qualitative data are presented in the next chapter, the results chapter, and will be presented in four sections to answer each of the research objectives.

Chapter 5

Results

5.1 Introduction

The overall aim of this study was to explore and evaluate the impact of a service-user led co-design intervention to improve service user and staff experiences on an adult acute psychiatric in-patient ward. The research question was:

Can a service-user led collaboration between staff and service users improve experiences on an adult psychiatric in-patient ward?

The study was undertaken in seven key phases as outlined in the methods chapter:

1. Baseline evaluation – pre-intervention
2. Observation of the process of the EBCD staff event
3. Interviews with people involved in the EBCD staff event
4. Observation of the EBCD joint patient & staff event
5. Interviews with people involved in the EBCD joint patient & staff event
6. Post intervention evaluation
7. Data Analysis

The following chapter provides the results of the study and is divided into two parts. The first part will briefly outline the timescale that the EBCD intervention was undertaken in and then will describes the key phases of the EBCD project as these unfolded in the research study.

The second part presents the findings relating to the four objectives as set out in the methodology chapter:

1. To prospectively study the implementation of a service-user led Experience-based Co-design (EBCD) intervention on an adult psychiatric in-patient ward
2. To explore whether such a service-user led co-design intervention can be successfully implemented in this setting
3. To measure the impact of the service-user led co-design intervention by comparing the ward atmosphere before and after its implementation and identifying any changes

4. To explore the role and impact of the service-user led group in the implementation of EBCD.

The second part of the chapter draws on the qualitative and quantitative data to support and illustrate the analytical findings.

5.1.1. EBCD timescale

The EBCD intervention as led by Research Net was completed in 18 months from start to finish, details can be seen in Table 5-1, this was in comparison to the 12 months that Robert et al (2015) state is how long a traditional EBCD process typically takes to complete. The start was defined as when Research Net had begun liaising with senior managers and the end of the project was defined as when they had completed the workstreams (as they did not undertake a 'celebration' event, as outlined in Chapter 3, within the traditional EBCD process).

Table 5-1 EBCD timescale

EBCD Stage	Timescale
Liaising with senior staff	July 2014
Observation of work area	August 2014
Interviews of staff	September – October 2014
Staff event	December 2014
Filming and editing of service user narratives	January – July 2015
Joint event	October 2015
Workstreams	November 2015 – January 2016

Results: Part 1

5.2. Phases of the evaluation of the EBCD project

The study was undertaken in seven phases as outlined in Chapter 4.

5.2.1. Baseline evaluation phase

The baseline evaluation phase was undertaken in two stages; firstly, through the author's attendance at the regular meetings held by Research Net during the period May 2014 and November 2014 prior to the beginning of the EBCD intervention in November 2014 and, secondly, via the pre-intervention Ward Atmosphere Scale being fielded on the case study psychiatric ward.

Research Net met on a weekly basis on a Thursday at 1pm for two hours at one of the Trusts' community mental health centres and the author attended six of these meetings on a monthly basis in the period before the EBCD intervention commenced. The meetings were typically attended by two members of staff from the Trust, a psychologist and an occupational therapist - and a core group of 6 service users who comprised the Research Net group in that geographical location. The chair of the meeting was rotated through the members of the group. Table 5-2 shows the characteristics of these Research Net meetings.

Table 5-2 Characteristics of Research Net meetings

Role	Participant pseudonym	Gender
Occupational Therapist	Nigel	Male
Psychologist	Ruth	Female
Service User	Karen	Female
	John	Male
	Flo	Female
	Alice	Female
	Denise	Female
	Peter	Male

The meeting was held in the same room; it was a large light room and the seating was arranged in a circle. Attendance at the meeting ranged from 8 – 12 people, but the core group identified in Table 5-2 above were always in attendance, the additional four people came from a variety of backgrounds, an assistant psychologist, a service user from another Research Net group and two staff members of other Research Net groups.

5.2.2. Observation of the EBCD staff event phase

The staff event was held in December 2014 in a large room in a hotel in the same geographical area as the psychiatric ward. The hotel was approximately 15 minutes' drive from the hospital site. The room itself was a generic hotel conference room; it was a neutral room with beige/mushroom coloured walls with a blue carpet. The room had three windows which gave a lot of natural light. There were paintings on the wall and it was a large room but not too big for all the people who were in attendance. There was a rectangular table at the front of the room with a screen behind it for presentations. In the rest of the room there were four round tables with chairs around each table for the audience/participants; each table had a mix of Research Net (two members on each table) and staff. I sat at the back of the room to observe. Table 5-3 shows the characteristics of the participants at the staff event.

Table 5-3 Characteristics of EBCD Staff event

Role	Participant pseudonym	Gender
Facilitator. Art Therapist	Norman	Male
Research Net staff member	Nigel	Male
Occupational Therapist		
Research Net staff member	Ruth	Female
Psychologist		
Research Net Service User member	Karen	Female
	John	Male
	Flo	Female
	Alice	Female
	Denise	Female
	Peter	Male
	Keith	Male
Occupational Therapist	Jim	Male
Ward Manager	Paul	Male
Staff Nurse	Kate	Female
	Hilda	Female
	Mark	Male
	Laura	Female
	Lauren	Female
	Simon	Male
	Meena	Female
	Zoe	Female
Health Care Assistant	Toby	Male
	Chris	Male
	Audrey	Female
	Ron	Male
	Harry	Male
Psychologist	Ken	Male
Modern Matron	Lee	Male
Consultant Psychiatrist	Ian	Male

5.2.3. Observation of the EBCD joint event phase

The joint event was held in October 2015, in a room in a hotel in the same geographical location as the psychiatric ward; it was not the same hotel as that for the staff event and was approximately a 20 minutes' drive from the hospital site. As with the room for the staff event it was a generic hotel conference room, smaller than the room for the staff event, and was neutral in colour, beige with a red carpet; there were no pictures on the walls. The room had two windows which gave natural light. The

room was furnished with four tables; there were three tables with chairs around them for people to sit around plus there was a table at front of the room for a laptop and projector for the facilitator.

As with the staff event, the tables were a mix of staff and people from Research Net on each. From the staff, there were a lot of the same people that had been at the staff event (although there were two members of staff less than there had been at the staff event, 16 as opposed to 18). Conversely there were more people from Research Net in attendance at the joint event as compared with the staff event: 14 (including two staff members of Research Net) instead of 9 and again there were a lot of the same people who had been at the staff event. I sat at the back of the room to observe. Table 5-4 shows the characteristics of the people that attended the joint event.

Table 5-4 Characteristics of EBCD joint event

Role	Participant pseudonym	Gender
Facilitator. Art Therapist	Norman	Male
Research Net staff member	Nigel	Male
Occupational Therapist		
Research Net staff member	Ruth	Female
Psychologist		
Research Net Service User member	Karen	Female
	John	Male
	Flo	Female
	Alice	Female
	Denise	Female
	Peter	Male
	Keith	Male
	David	Male
	Kim	Female
	Iona	Female
	Klara	Female
Occupational Therapist	Jim	Male
Ward Manager	Paul	Male
Staff Nurse	Kate	Female
	Hilda	Female
	Laura	Female
	Lauren	Female
	Meena	Female
	Cathy	Female
Health Care Assistant	Toby	Male

	Chris	Male
	Audrey	Female
	Ron	Male
	Harry	Male
Psychologist	Ken	Male
Modern Matron	Lee	Male
Consultant Psychiatrist	Ian	Male

5.2.4. Post-intervention evaluation phase

The post-intervention evaluation phase was carried out on the same ward where EBCD was implemented. As in the pre-intervention phase the ward had 20 beds and had 24 members of staff to support these patients who had similar characteristics as those outlined in section 5.2.1 above.

In April 2016, all 20 patients and all 24 staff who were on the ward 6 months after the EBCD joint event had been held were approached to complete the Ward Atmosphere Scale. A total of 15 patients and 14 members of staff completed the survey.

5.3. Characteristics of the study participants

As the study sought specifically to explore and understand the experience of being involved in an EBCD project a total sample of all those who participated were invited to be interviewed. From the 28 people who attended the staff event, nine agreed to be interviewed (four members of staff and four members of Research Net and the facilitator). Of the 30 people who attended the joint staff and patient event, nine people agreed to be interviewed (four members of staff, four members of Research Net and the facilitator). All those who agreed to participate were interviewed and their interviews were audio-recorded and anonymised. In total 11 people involved in the EBCD project participated in the semi-structured interviews and a total of 18 interviews were undertaken (as some of the participants were interviewed twice, following both the staff and joint events).

Table 5-5 Interviewees

Interview point	Name	Role
Following both events	Paul	Ward manager
	Norman	Facilitator
	Kate	Nurse
	Lauren	Nurse
	Nigel	Staff member of Research Net
	Karen	Service user member of Research Net

Following staff event only	John	Service user member of Research Net
	Toby	Health care assistant
	Peter	Service user member of Research Net
Following joint event only	Ken	Psychologist
	Alice	Service user member of Research Net

The eleven people who were interviewed included (see Table 5-5) a ward manager, three mental health nurses/health care assistants, a psychologist, four service users and one staff members of Research Net, and the facilitator of both the staff event and the joint events.

Results: Part 2

5.4. The research objectives

The following section presents the results in relation to each of the four research objectives. Each objective was addressed in a specific phase of the study and by one or more data source. Table 5-6 outlines the relevant objective, study phase and data source(s).

Table 5-6 Research Objectives by phases and data sources

Number	Research Objective	Phase	Data source
1	To prospectively study the implementation of a service-user led Experience-based Co design (EBCD) intervention on an adult psychiatric in-patient ward	2 & 4	Ethnographic observation. 10 hours & 55 minutes)
		2-5	Semi-structured interviews (n=18)
2	To explore whether such a service-user led co design intervention can be successfully implemented in this setting	2 & 4	Ethnographic observation. 10 hours & 55 minutes
		2-5	Semi-structure interviews (n=18)
3	To measure the impact of the service-user led co design intervention by comparing the ward atmosphere before and after its implementation and identifying any changes	1 & 6	Pre- and post-measurement using Ward Atmosphere Scale
4	To explore the role and impact of the service-user led group in the implementation of EBCD.	3 & 5	Semi-structure interviews (n=18)

5.5. Research Objective 1

To prospectively study the implementation of a service-user led Experience-based Co-design (EBCD) intervention on an adult psychiatric in-patient ward

Both the staff event and the joint event were observed; I sat at the back of each room and took field notes which are drawn on throughout this chapter. During the events I made notes about who contributed to the process, who was actively involved in the event and who was not, as well as the interactions between attendees at each event. I observed and recorded the process of EBCD as implemented in this specific mental health setting and studied how closely they adhered to the EBCD toolkit as outlined in Chapter 3. The field notes were explored using thematic analysis; the themes relevant for research objective 1 will be presented here.

Table 5-7 presents the key features of the staff and joint events.

Table 5-7 Features of the staff and joint events

Parameter	Staff Event	Joint Event
Length of meeting	300 mins	280 mins
Number of staff in attendance	18	16
Number of Research Net members in attendance	9	12
Time spent adhering to EBCD toolkit and a percentage of total time for the event	159 mins 53%	161 mins 57%
Time spent discussing issues raised during event and as a percentage of total time for the event	20 mins 6%	23 mins 8%
Time spent in co design and as a percentage of total time for the event	80 mins 27%	81 mins 29%

5.5.1. Time spent adhering to the EBCD toolkit

This section presents what happened at each of the events in terms of time spent adhering to the EBCD toolkit and includes the author's reflections on whether the EBCD intervention as originally developed in acute care settings can be implemented with high fidelity in an acute mental health context.

In the staff event, 53% of the time or 159 minutes was spent adhering to the relevant part of the EBCD toolkit. For example, the facilitator spent time outlining the EBCD process and describing the observations that Research Net had made whilst they were

on the ward as well as presenting reflections following Research Nets interviews with staff. The rest of the time for the staff event was spent discussing other issues raised and also being involved in co-design.

During the presentation of the EBCD process, it appeared that there was a general acceptance of EBCD as a QI process that could be applied to a mental health setting:

Facilitator standing and explaining EBCD process, described what had been done to get to this point, discussed observations and interviews, feedback observations, acknowledged it showed staff were working hard, I.D's difference between permanent & agency staff.

- Author's reflection, Field notes, observation of staff event

Attentive staff, looking at presenter, some nods around the room, paying attention

- Field notes, observation of staff event

A key component of the EBCD process at the staff event is to feedback insights gathered through the earlier non-participant observations and staff interviews. The facilitator highlighted key observations of the ward environment, which were:

1. Hardworking staff
2. Patients waiting
3. Agency staff not fitting into ward culture
4. too ward round focused

The facilitator then went on to then reflect on what it must be like to be a patient on the ward. This was a theme that Research Net - as the observers and interviewers - had picked up and highlighted. The author's reflection on this part of the event was that there was an acknowledgement of the issues being presented as valid and important:

All staff sitting in silence, most looking at the facilitator, some looking at the table in front of them, whilst a couple of staff were whispering to each other, most were not talking, there were lots of nods around the room.

- Field notes, observation of staff event

Time was then spent identifying what the emotional touchpoints were for a patient from the staff's perspective. The author's observational notes of this highlight that:

The facilitator led a discussion on a patient journey into the ward and the emotional touchpoints along that journey; the facilitator asked the

room to consider patient touch points and asked each table to think about what type of patients Research Net should interview

- Field notes, observation of staff event

Time was also spent by some members of staff using the opportunity of the staff event to express concerns and issues about the ward that were not related to Research Nets observations of the ward or their interviews with staff, this is appropriate, as part of the reasoning for a separate staff event is to allow for this type of venting. The consultant psychiatrist arrived late at the staff event and then spent the next 25 minutes explaining the difficulties the doctors face on the ward and what should be done to resolve these issues.

The consultant psychiatrist arrives late for event, doesn't seem know why he is there, seems very unsure what EBCD is all about, discusses pressure and issues that the Dr's are facing on the ward and that they need more resources and more support to do their jobs.

- Field notes, staff event

By contrast the issues that were discussed at the joint event were mainly centred on discussing issues that were related to the EBCD process, it felt as though more of the staff at the joint event were aware of the EBCD process, which was to be expected.

1st comment from the Dr reflecting on what he had been doing on the ward, reiterated issues from the staff event – still seems unsure about EBCD. Two nurses had a discussion about NHS nursing shortages and how this was affecting their ward, then took the opportunity to make a plea from more nursing staff on the ward

- Field notes, joint event

The author's reflection on this part of the staff event is that - because of the presence of members of Research Net on each table - it moved from adhering to the EBCD process as set out in the toolkit to actually beginning the co-design process:

Really good discussion from tables 1, 2 & 4. Table 3 nodding. Staff on table 2 highlighted patient touch points, good understanding of the process. Discussions started by everyone introducing themselves, all actively engaged in the process and in discussions, all four tables quickly became actively engaged in discussing emotional touch points on the patient journey, [Authors reflection: having Research

Net here has, the author feels, started the EBCD process earlier than traditional EBCD projects].

- Field notes, observation of staff event)

At the joint event 161 minutes - over half the time (57%) - was spent adhering to the EBCD process. This was predominately the showing and discussion of the four films made by Research Net, which are a key part of the EBCD process. As with the staff event, the facilitator introduced the joint event by reminding the room of the EBCD process, and then described what had happened at the staff event and in the period between the two events.

The facilitator kicked off the event, reminded everyone what had happened at the staff event, recapped on what EBCD is actually about, reminded the room about the observations from Research Net: 1) Hardworking staff, 2) Patients waiting, 3) Agency staff not fitting into ward culture, 4) too ward round focused

- Field notes, joint event

During this part of the joint event, the whole room - staff, service users and members of Research Net - appeared to be actively engaged:

All in room were paying attention, lots of nods from all three tables in recognition of what was being said. Lots of conversations and nods from staff and members of Research Net, seemed to be in agreement with what was being said. A member of staff from table 1 agreed with the reflections, a member of Research Net on table 3 agreed with the reflections and added comments

- Field notes, joint event

The next key part of the EBCD process at the joint event is the introduction and showing of the films that had been made; this part of the joint event took 59 minutes and included the films being presented, followed by a discussion around what the films were revealing.

The facilitator identified that there were a series of four films of patient experiences, based around four themes:

1. Tell us about your admission
2. Positive points in the admission
3. Less positive experiences
4. What could be improved?

Observations that were highlighted at the staff event and that the facilitator reminded the room formed some of the content of the films and subsequent table discussions.

The facilitator introduced the concepts of the films, asked people to jot down emotions and points that were raised during the films, said the films were spilt into four parts

- Field notes, joint event

The joint event closely followed the traditional EBCD process with staff and service users being on the same tables, watching and discussing the films. The author's reflection of this part of the event was;

Everyone grabbed pens and pads of paper that were on the tables, staff clearly noticed that members of Research Net were sitting on the tables with them were also in the films telling of their experience of being on a psychiatric ward, everyone was making notes as directed by the facilitator.

- Field notes, joint event

The next stage in the EBCD process is for the mixed group of staff and patients on the tables in the room to begin to feedback their responses to the films. Within the traditional EBCD process this is the beginnings of co-design; staff and patients watching the patient experience films together, discussing them and agreeing on the issues raised. The first of this series of patient experience films to be shown was 'tell us about your admission, the film was approximately 5 minutes long and consisted of a series of interviews with patients about their experience of being admitted to a psychiatric ward. The image on the screen was the patients head and shoulders only. The author's reflection on this part of the joint event was that co-design was underway and the EBCD process was being effectively implemented:

All three tables participated in discussions, very open conversations. Research Net on each table seemed initially nervous, but very quickly opened up and discussed how their admission felt to them. Nurses

on table 1 reflecting that that was how they felt when they first went onto a psychiatric ward as a student nurse

- Field notes, joint event

The co-design aspect of the EBCD process continued in the summing up of the tables discussion; members of Research Net gave the feedback (although this did not appear to have been planned but rather happened naturally):

Tables began to sum up their discussions, 'it really feels as if co-design is already starting', doesn't feel like a 'them and us'. Staff on table 1 reflecting that they don't stop to think how it feels for patients. Staff seem to be beginning to empathise with patients. Table 1 gave feedback, led by member of Research Net, staff supported her, not talking over her, but adding to her comments, lots of joint working. Agreement as to touchpoints being; Scary, Confusion, Waiting and Isolation.

- Field notes, joint event

The second film to be shown was 'positive points about your admission'. As with the first film, this was approximately 5 minutes long and also consisted of a series of head shot interviews with patients about the positive aspects of their admission. The response was similar to that to the first film with one exception; the staff on the tables seemed reluctant to start talking (this was the same on all three tables) until members of Research Net had initiated conversations. There could have been a number of reasons for this but the author's reflection was:

As it was about positive experiences, it appeared to me (author) that staff seemed reluctant to start talking, it seemed almost as if the staff are either reluctant to acknowledge their good points or they are too modest. Agreement to touchpoints being; normality, talking, safety, personal touch.

- Field notes, joint event

As with the response to the first set of films, once started, conversation on each table was collaborative and everyone joined in.

Lots of conversation on all three tables, laughter and agreement, the room feels very positive, each table is reflecting on the points that have been brought up.

- Field notes, joint event

The third film was about 'less positive experiences'. Similar to the first two films, this was a series of interviews with patients, about their less positive experiences of admission. Once this film had finished, the facilitator did not need to direct the room as to what they needed to do; notes were taken on each table, conversations began. All members of staff were actively involved in the discussions.

Facilitator didn't need to ask for tables to begin discussions, lots of spontaneous conversations began on each table, initially about night staff, but then on all aspects of the film segment. The Dr now more involved, now seems to understand EBCD more than they did at the staff event (It was the same Dr at both events). Agreement as to touchpoints was communication, night time, unsafe

- Field notes, joint event

The final film was interviews with a number of patients and was approximately 5 minutes long and was about 'what could be improved', it focused on less positive experiences of being admitted. Again, there was no need for the facilitator to direct the room; all tables began taking notes and then as soon as the film stopped, discussions started. Conversation seemed to be centred around treating each other as human beings, rather than staff and patients:

A member of Research Net feedback from table 3, lots of discussion around the room about what it means to treat each other as humans. Good interaction observed between staff and patients. Agreement as to touch points as; communication, everyone's human, more difficult at the beginning, Face to face.

- Field notes, joint event

The final stage in the EBCD process at the joint event was for attendees to agree on the issues they wanted to focus on and to identify the work stream or work streams that would develop and implement changes relating to the agreed issues. This process was followed at this stage of the joint event, with the facilitator directing the room to discuss on their tables and identify three areas that they wanted to focus on in the work streams:

People paying attention, all back from the coffee break on time, all seem keen to continue discussing films and the issues, everyone participating, no one disinterested, everyone paying attention to each other, not speaking over each other. Everyone seems to have an

equal voice; health care assistant has equal input as the consultant psychiatrist, as does a member of Research Net.

- Field notes, joint event

Discussion and feedback from each of the tables indicated an adherence to the EBCD process and high levels of active engagement. Feedback was provided by a member of Research Net on each table, but support was evident from all.

The facilitator then summarised the 4 key areas based on the room's discussions as:

1. Admissions
2. Activities
3. Routine
4. Paperwork

The facilitator asked the room to vote on the work stream to be taken into the co-design phase of the EBCD process; the room decided to focus on one work stream only as they felt that this would give it more chance of success. The room picked admissions and choose this area to focus on for their workstream.

5.5.2. Time spent discussing issues raised during event

This is the time spent during the events that the author identified as separate to the time spent adhering to the EBCD process in the previous section. This will highlight other issues that the author felt important to explore further, as part of the observation of both events.

There was a slight difference between the amount of time that was spent discussing these issues at the staff event, compared with the joint event; 20 minutes compared with 23 mins. The predominate reason for this appeared to be that during the staff event, time was taken up by the staff in the room discussing issues that were separate to the feedback of Research Nets observations and interventions, staff highlighted issues within community teams. Interestingly no one from the Research Net group discussed anything that wasn't related to the EBCD process.

Director of service talked about pressures in community teams and that there needs to be an understanding of these difficulties

- Field notes, staff event

5.5.3. Semi-structured interviews

To help address research objective 1, semi-structured interviews were also conducted with nine participants at the staff event and nine participants following the joint event. The interviews were undertaken after the observations of the events had been completed. The purpose of the interviews was to explore with the participants, both staff, members of Research Net and the facilitator's perception of the service user led EBCD intervention.

The characteristics of the interviewees have been described earlier in this chapter in Table 5-5

5.5.4. Implementing a service user led EBCD intervention

Analysis of the interview transcripts led to five key themes emerging in relation to staff and Research Net members' perceptions of the implementation of the service user led EBCD intervention. These included:

- EBCD awareness by participants of process
- Potential improvements to care following process
- Emotional response to process
- Staff/patient collaboration
- Power imbalance

Table 5-8 present the sub-themes within each of these:

Table 5-8 Themes and subthemes: implementing a service user led EBCD intervention

Themes	Sub themes
EBCD awareness	Understanding of EBCD process Limited understanding of EBCD process Sceptical of EBCD
Improvements to care	Expectations Optimistic Pessimistic
Emotional response to process	Anxieties Bad memories Staff uncomfortable Feeling criticised Concerns Positive response Cathartic process Improves confidence
Staff/patient collaboration	Collaboration with patients/staff Positive impact of patient/staff collaboration

	Working as a team
	Breaking down barriers
	Hope for positive impact
	Negative impact of patient/staff collaboration
	Concerns re collaboration
Power imbalance	Senior managers and staff
	Staff and patients
	Patients and staff

Each of the five themes (and the sub-themes within each) are now presented in turn below.

5.5.5. EBCD awareness

This theme and its sub themes emerged from responses to the interview questions to the staff and members of Research Net about their experience of being involved in the EBCD intervention. It included sub themes of understanding, lack of understanding of EBCD process and also included scepticism of EBCD

Awareness of EBCD ranged from limited understanding all the way through to a full understanding of the EBCD process and the steps that would be involved in implementing an EBCD quality improvement project. This wide range of understanding did seem dependent on whether the individual interviewed was a member of staff or a member of Research Net.

Lauren, a member of the nursing staff had some limited understanding of EBCD. She stated that she had been interviewed by one of the members of Research Net prior to the staff event and understood that feedback from this would happen at the staff event. However, she still seemed unsure as to the purpose of the staff event:

“I thought it was nice to see all of my colleagues, it was nice ‘cause it’s very rarely that we are all together because its shift work. We got a chance to all talk about things as a proper team, which we rarely get to do.”

- Lauren – Staff Nurse, post staff event

Another staff nurse said they were aware of what the EBCD process was all about but did not expand on this:

“Aah, I have been interviewed previously and had some information via e-mail about the process and what it was supposed to be about.”

- Kate – Staff Nurse, post staff event

Not all staff had limited awareness of the EBCD process; some had a greater understanding even though they had not been interviewed by Research Net. Increased understanding for staff members seemed to stem from the individual member of staff's own take on quality improvement projects for patient experience, as exemplified by Toby - a health care assistant - who stated:

“Ok, so Paul (ward manager) made us all aware via emails and that, and in business meetings we were going to get involved in, and then basically picked out a few staff that you know, that might benefit the project. So he picked myself and a few other people that would get behind it cos I am quite interested in like patient experience, so from my understanding it's about with working with clients to in partnership to best design a more user friendly practice”

- Toby – Health Care Assistant, post staff event

It is perhaps this natural affinity to improving the patient experience that led Toby to a greater awareness of EBCD; later in his interview he was able to give quite clear understanding of the next steps in the EBCD process.

“As far as I'm aware it moves forward to recording some interviews, get more feedback and you know working together with patients to design some kind of template we can use to improve care to best benefit you know like be more mindful I guess of patients' needs from their perspective, which we don't always have the luxury of doing in nursing.”

- Toby – Health Care Assistant, post staff event

Toby's comments were in contrast to those of Kate and Lauren who were less certain of the next steps for the EBCD process. Kate, when directly asked what she understood would happen next replied:

“No, you know, it seems to me that there is going to be a joint thing, but it seems a bit separate, it seems like its EBCD, then we are pulled in to do our staff interviews, then they pull us in to present what they have found and they go off and interview past patients and then they are presumably going to come and feed that back to us again and then what happens? Who in the end is gonna make up the rules, is it the EBCD, is it us, is it the patients?”

- Kate – Staff Nurse, post staff event

Amongst the staff, whatever their level of awareness of the EBCD process, there did seem to be some scepticism about what EBCD could or would achieve in terms of outcomes. Both Toby and Kate expressed doubts about what EBCD could achieve.

“...I don’t think they told us anything we didn’t really know already, no offence, we know we are understaffed, we already know there is too much paperwork it’s what we do about that and I wonder how, I don’t know, trying to look at it from a patient’s point of view if, I don’t know how that works.”

▪ Kate – Staff Nurse, post staff event

Toby echoed concerns about whether EBCD could make any difference due both to the process of EBCD and whether it could be implemented on the psychiatric ward:

“...the discussion at the staff event was great, but you need a hell of a lot more than just one chat about it to, cos it’s a huge undertaking and it needs a hell of a lot more staff input and staff contribution to create, you know, the co-design aspect so far is coming from their side, the side of the patients and not from the side of the nursing staff...”

“I just think lot of staff are quite negative, I am one of the more positive ones, but then you know it’s hard you know being the only positive one...it’s the whole, it’s all the pressures we have, you know it just, it hinders, it hinders and kind of you know progressive plan being implemented...Cos of all the demands”

▪ Toby – Health Care Assistant, post staff event

Norman, the facilitator of both events was unsure there would be an impact on the ward through the EBCD process, as he felt that the staff were very unsure about EBCD and why they had been picked for the project:

“It’s a ward, they are not particularly happy at having EBCD, there’s some suspicions about, they’re thinking is it an investigation.”

▪ Norman – facilitator, post staff event

The members of Research Net, in contrast to the staff and as expected given they were leading its implementation, were far more aware of the EBCD process. The members of Research Net expressed their awareness of EBCD through discussion and comments about the actual process. John was asked about what the next stages were and he replied.

“Well it’s getting the service users interviewed now, some of us are going to take part, to interview and be interviewed, doing both, but obviously different days and do a bit of filming, leading up to the interviews we will have a couple of days on the um reception asking patients if they would like to be interviewed.”

- John – Service User Member of Research Net, post staff event

Such clear statements about the processes of EBCD were repeated by Nigel, a staff member of Research Net, who described what they did at the beginning of the project with the observations on the ward.

“I found it interesting and a very important thing to do because you really see the say cut and thrust of what it is like being on the ward by just being there, observing the comings and goings, the interactions or lack of...”

- Nigel – staff Member of Research Net, post staff event

In their descriptions of EBCD, members of Research Net emphasised their own role in planning of the project as can be seen in Nigel’s response to his expectations for the staff event:

“We planned it quite well cos we decided who was going to sit at each table, didn’t decide who they were gonna be except we decided what Research net people were to sit where, we worked that out which table, and that was the main thing we discussed with the group clearly, what the purpose of the day was and that they, and they rose to the challenge, cos in a way it was quite a step up to affectively chair a table of discussion with ward staff”

- Nigel – staff Member of Research Net, post staff event

Following the joint event, awareness of the EBCD process increased amongst the staff. This was particularly noticeable with Kate, a staff nurse who had been interviewed following the staff event and had previously demonstrated limited understanding of the EBCD process. Kate had a greater understanding of what the next steps were in terms of the co-design work streams:

“Yes, they [the films] were interesting to watch... it was nice to hear some positives, because this process, I suppose we are looking at the bad things, the things we could improve, and make better... following the videos we are going to work on the admission, I think it

opens your eyes to that first hour and how important that is, but also it is very difficult sometimes when you have a chaotic ward and you are bringing somebody new in, to actually allow that time, but I guess the videos have shown us that we need to try where we can and do that as much as possible so hopefully if we can improve on that it will be better than what it was.”

- Kate – Staff Nurse, post joint event

Other members of staff were aware of what should have happened at the joint event and were also fully aware of the next steps in the EBCD process. Ken, a psychologist on the ward, explained his understanding:

“We’re going to work on the admissions, I really feel – I think it’s a great idea. As much as I was unsure about the ‘golden hour’ idea, the actual admissions process – absolutely, and it’s a great place to start and I think it has been given focus before, but it hasn’t in this way and that’s good and I do feel quite enthusiastic about it.”

- Ken – Psychologist, post joint event

5.5.6. Improvements to care

The second key theme in exploring research objective 1 was participants, both staff and members of Research Net, expectations of what would happen as a result of the EBCD intervention. These expectations were both optimistic and pessimistic and are now presented.

Following the staff event, members of Research Net were cautiously optimistic that EBCD could improve care. Karen - a service user member of Research Net - was hopeful care would improve and said:

“I hoped we’d be able to work together and see how we can make changes and make things better for the staff and the patients.”

- Karen – Service User Member of Research Net, post staff event

This was supported by John, another service user member of Research Net, who was also hopeful that through the process of EBCD care would be improves. He said:

“Yeah we were getting, tried hopefully to get some patients interested in attending the interviews, to hear their experience of how they felt when they were ill, treated in the ward. What they thought was good

and bad...what we could improve on and everything like that, I think it will make a difference.”

- John – Service User Member of Research Net, post staff event

Nigel, a staff member, although hopeful of improvements to care, was more cautious. He said:

I suppose the other concern is that staff will then be able to respond to that in a way that will change their practice and change their thinking and help them click into the redesign cos, I don't think they get that yet.

- Nigel – Staff Member of Research Net, post staff event

Staff, conversely, either did not mention any possible improvement to care, or actually stated they did not feel it would make a change at all. Toby felt was due to the staff themselves:

“Urm, I think it might help, it could be, if it worked well, it could be beneficial but I don't think, I've very little confidence in it succeeding to implementation and becoming the norm...I just think a lot of staff are quite negative to it...you know and then everybody just putting it down and finding other things to keep themselves busy.”

- Toby, health care assistant, post staff event

Such reservations did however change following the joint event when interviewees - both members of Research Net and staff - voiced expectations that care would improve. Paul, the ward manager, said:

“I am hoping that they will (patients) feel and see that the process has actually made some improvements to the way that the admission goes forward, that there are less obstacles, more streamlined, more focus and less cumbersome. If we streamline it, hopefully we can improve it from both sides, for staff as well.”

- Paul – ward manager, post joint event

Paul was also hopeful that there would be a positive impact for staff as well. Karen, a service user member of Research Net, also had expectations that care would improve and change the way that patients experienced an admission to a psychiatric ward:

“The clients' needs will be met, and listened to and, the admission you know, just make it nicer because it is daunting. I know when I

went in there I was so frightened, as I had never been on a ward before like that, and there were lots of unwell people and it can be quite frightening.”

- Karen, service user member of Research Net, post joint event

5.5.6. Emotional response to the process

The theme that appeared to be discussed and raised the most during the interviews were the emotional responses from staff and Research Net to being involved in the EBCD process; sub-themes included anxieties, concerns and positive impact.

Following the staff event, there was a marked difference in emotional responses from members of Research Net and the members of staff; members of Research Net were anxious about going back onto psychiatric wards. Peter a service user member of Research Net said:

“I wasn’t involved in the observations for personal reasons as I was sectioned for 6 months, it was a long time ago and it wasn’t even at the hospital where the observations were, but I felt uncomfortable going into the ward...brings back a lot of memories and just being there it brings it all back, so I didn’t actually get involved with the observations”

- Peter – Service User member of Research Net, post staff event

This anxiety was echoed by John, another service user member of Research who said,

“It brought back a lot of memories, as I was there before, I was a patient on the ward we did the observations on. I was there a long time ago for two weeks max, I recognised a lot of staff there as well, but I don’t think they recognised me. It brought back memories, I had to learn to put things in the back of my head.”

- John – Service User member of Research Net, post staff event

Despite the anxieties around going back onto psychiatric wards where they either had been patients or wards that reminded them of a ward they had been on, members of Research Net described the process of being involved in EBCD as having a positive, cathartic impact:

“I interviewed the matron and it was really interesting finding things out from the other side from being a patient, yeah I found it so interesting and it helped me to cope with the things I had been

through knowing that, cos when I was sectioned I felt threatened by all the staff, but when I did the interviews I realised you know that they are there to help and they have a really hard job.”

- Peter – Service User member of Research Net, post staff event

John, another service member of Research Net shared Peter’s feeling of being involved in EBCD as a cathartic process and said.

“It’s all positive, cos I can relate to know that’s there and then what is going on at the time, so through the interviews and everything, yeah I can sort of relate to it and understand where they are coming from, it helped me.”

- John – Service User member of Research Net, post staff event

One of the benefits that service user members of Research Net highlighted was that they felt that being involved in the EBCD had improved their confidence. Karen described how she felt actually being on the ward to undertake the observations:

“I didn’t feel anxious, cos I thought I am well now and so I have got to say that I have recovered and I can go on there and I won’t be nervous or frightened and I felt secure as I know the staff there.”

- Karen – Service User member of Research Net, post staff event

This was supported by John, another service user member of Research net who described how he felt when they facilitated the staff event:

“At Research Net, we depend on confidence building, going in there in the event, I was excited to do it, I didn’t know what I was letting myself in for. But everyone was focussed on what they were doing, everything came into play, what we’d talked about previously and the discussions in the meetings, people just went forth into their slots, so you know it kinda went well.”

- John – Service User member of Research Net, post staff event

The impact of being involved in an EBCD project on people’s confidence was also noted by Nigel, a staff member of the Research Net group, who described how he felt the members of Research Net facilitated the staff event:

“We discussed what the purpose of the day was and they rose to the challenge, cos in a way it was quite a step up to effectively chair a table of discussion with ward staff, so I was impressed with how they

got on with it, they looked like they had been doing it for years, there was nobody thinking 'oh my lord I can't do that', there was nobody having an anxiety attack, they just said, 'ok I'll do that table, you do that table', it all worked really well. It will pay off in the long term in their confidence and their feeling that they are doing service redesign, service development and contributing to improvements."

- Nigel – staff member of Research Net, post staff event)

One service user member of Research Net, Karen, expressed a sense of pride in being involved in the EBCD project. She described how she felt when she was on the ward undertaking the observations:

"There were a few members of staff that I recognised and they were pleased to see me and see that I was doing well. I got positive feedback, cos as soon as they saw me they were like so pleased and happy that I was well and it sort of made their day seeing me you know, that they had helped me get to that stage of recovery and be able to move on and do something else."

- Karen – Service User member of Research Net, post staff event

Staff when interviewed following the staff event also had anxieties about EBCD; these related both to the actual EBCD process and also to working alongside service users:

"We raised quite a lot of concerns when we first heard about it, in terms of patients that were still within our service or had even used the ward before and currently and maybe sitting in on other patient discussions and things like that, that was concerning. If they become unwell and come back they are not necessarily going to agree to the terms they agreed to when they were well, my concern is that they would go up to a patient that they had listened to a hand over in and start revealing information about them."

- Kate – staff nurse, post staff event

Service user members of Research Net also described anxieties around the actual process of EBCD, although their anxiety was more to do with being involved in the early stages of EBCD:

"I was a bit anxious about doing the interviews, I did one the other week and I thought 'am I using enough eye contact, am I not making noises', because we were told not to make sounds when you are

interviewing, just sit there and nod your head and that, and I was a bit nervous and then I got positive feedback and then it seemed it was really good, so I was worrying about nothing.”

- Karen – Service user member of Research Net, post staff event

Service user members of Research Net also described anxieties about the impact on current service users that they were interviewing:

“I wasn’t too nervous, but I was more worried about the after affects, cos you know...after the interviews quite often those who had been interviewed...which I have experienced quite a few times myself when I have been interviewed, not straight away, but normally on the same day, three or four hours later you feel traumatised. You could be sitting on the settee watching something, and it all comes back to you.”

- John – Service user member of Research Net, post staff event

Service user members of Research Net, in response to this potentially traumatising impact on interviewees had set up a support group for service users, as described by Peter:

“Me and ‘Karen’ are going to be doing a support group for people that are being interviewed, just in case it brings up any emotions or thoughts, we’ve already done one interview and me and Karen sat with her after the filming and we had a little chat and she said that really, really, really helped her. So hopefully me and Karen will be able to support and help people.”

- Peter – Service user member of Research Net, post staff event

Staff described working alongside service users, some of whom had been patients on the wards that they worked on, as uncomfortable and unsettling. Kate a staff nurse on the ward said,

“The patients observed the ward, sat in a few ward rounds, that didn’t feel very comfortable. I think in terms of patients that had not been here for a quite a while that felt more comfortable than patients that had maybe been here in the last six months; it didn’t feel right.”

- Kate – staff nurse, post staff event

This view was supported by another member of staff, Toby, who described being involved in the EBCD process with patients they had nursed as unsettling:

“That was quite unsettling, especially with, I won’t mention names, there was definitely a couple who you know, particularly one in particular, one patient in particular we thought, we, or personally I questioned her motives for getting involved in the project, you know, considering how critical she was of ward practice throughout her admission.”

- Toby – health care assistant, post staff event

Staff had a big anxiety that they were actually going to be criticised through the EBCD process:

“Well it was more about, are we going to be scrutinised, is it going to be a spotlight on what nurses maybe doing wrong and another thing about critical with nurses and picking holes.”

- Toby – health care assistant, post staff event

Emotional response to the process continued as a theme in the interviews after the joint staff and service user event. The service user members of Research Net continued to find their involvement in the project a positive experience:

“I was quite pleased to make a difference, doing the films and spending time with the staff, listening to them and hope they would see what we were trying to do, see we were making a difference and not to criticise, make positive steps. When they saw the films, it was lot better than I thought, I thought, you know, I went in there with a slight anxiety, but I started seeing it and noticing things in the room and I thought it really wasn’t that bad.”

- Karen – Service user member of Research Net, post joint event

Karen described how she felt her involvement in the EBCD project had improved her confidence:

“I feel it has helped me a lot, because I feel I am to express myself now and I feel with a lot of help from people it’s made me see that I am getting better, I am better. I am able to talk about things, and it doesn’t upset me and I can talk about how it was for me when I was unwell and I can still get on the next day and it doesn’t bring me down

and I have got a better understanding of myself and I deal better about myself. I feel it has helped me confident wise, I feel it's a lot better than it was."

- Karen – Service user member of Research Net, post joint event

The staff on the ward continued to remain anxious about the process of EBCD with the ward manager expressing concerns the process focused on service users.

"I don't think it's thought about from a staff perspective; it is client focused, which I can understand, but as I've said it's not always necessarily all about the patient, it should be about the two parties that are in that relationship."

- Paul – ward manager, post joint event

Service user members of Research Net also continued to be anxious about the process of EBCD, but this anxiety continued to be expressed in terms of actually carrying out the steps in the process.

"I was anxious, to be honest, I didn't know if I asked the right questions, wasn't sure if I left them enough room to answer the questions, making sure I didn't interrupt and making sure they are left to have their say and what they want and get my questions across, I think it went ok."

- John – Service user member of Research Net, post joint event

An interesting response from one member of staff was a concern about how staff would respond to the films:

I was concerned that the impact of the videos was going to be quite emotional, or maybe defensive at times, a dollop of defensiveness. I was worried that the staff would be able to hear what was being said on the videos and listen rather than just being angry and defensive.

- Ken – Psychologist, post joint event

Following the joint event, it appeared from some of the staff's comments that concerns and anxieties that they had about being involved in the EBCD process and in particular about working alongside service users were beginning to be alleviated:

"The tables were mixed up, so it didn't feel like a them and us and it was nice to see one of the Research Net, I don't actually know the person's name, but when we met the first time she was quiet and

didn't really interact a lot, but this time she was interacting – she looked different, she looked like she had recovered a bit. It was nice to see that actually she had got engaged with the process and she was doing something meaningful.”

- Kate – staff nurse, post joint event

5.5.7. Staff-patient collaboration

The fourth key theme in exploring research objective 1 was staff patient collaboration; this theme included sub themes of collaboration with patients/staff, positive impact of patient/staff collaboration, working as a team, breaking down barriers, hope for positive impact, negative impact of patient/staff collaboration and concerns re collaboration.

Following the staff event, there was a difference in how members of Research Net and the staff expressed the theme of staff patient collaboration. Members of Research Net were overwhelmingly positive whilst the staff expressed concerns.

Nigel - one of the staff members of Research Net - talked about how the staff members and service user members of Research Net worked as part of a team:

It was good that myself as a paid member of staff was together with the service users, we were together as a team, they were involved from the very beginning, it was really important and they were very enthusiastic about it, being there seeing what was going on, wanting to take an active part, which was encouraged.

- Nigel - staff member of Research Net, post staff event

Nigel also talked of how staff-patient collaboration broke down the barriers between staff and patients and described his impression from when the service user members of Research Net first went onto the ward to undertake the observation:

“There was a warm friendly welcome from staff who knew them, which helped and it was good for staff to see people who had been patients, who had been on the ward and who are now doing well and I think any anxiety that the service users had didn't last long.”

- Nigel - staff member of Research Net, post staff event

Karen described the staff-patient collaboration at the staff event which she felt was positive:

“I think we all worked well and it seemed that everyone was really chatting well around the table, everyone was getting on with each other at the event, I think we were able to share ideas and things we found out and it was good and positive feedback, I was a bit worried about what the staff would think about what we had reported, but they were really good.”

- Karen - service user member of Research Net, post staff event

Another service user member of Research Net, Peter, described how positive he found the staff-patient collaboration at the staff event:

“Just talking to staff on our own, we were all on different tables and talking about things that we can do to help, what we can do to make changes on the ward, I really enjoyed it, the tables were great, it was a really good conversation, I learnt a lot.”

- Peter, service user member of Research Net, post staff event

Norman, the facilitator, also described what he saw as the positive impact of the staff-patient collaboration at the staff event, with staff and members of Research Net together of the same tables:

“Yeah I think it was quite amazing, one of the members of Research Net, was able to go back and remind staff that she was their patient and she in a very positive way was a patient and a researcher and so I think she was a fantastic bridge builder.”

- Norman – facilitator, post staff event

Staff on the other hand were more cautious about the staff-patient collaboration and expressed some concerns about staff and patients working together. Kate, one of the staff nurses described how she did not think it would be an effective collaboration as she felt staff would not be honest in their conversations with service users:

“I think it would maybe limit the discussions we had, by maybe people not wanting to say what they really felt, because they didn’t want to offend anybody or maybe not say anything if they weren’t sure how to put it, so they didn’t offend anyone they didn’t bother saying anything.”

- Kate - staff nurse, post staff event

Such concerns about saying the right thing or not saying the right thing was repeated by another member of staff who - although he felt there were good discussions on the tables at the staff event - expressed caution:

"Yeah, we did discuss a lot, you know it's good for us all to be able to do that, good to have the opportunity to be able to discuss things like that, but I dunno, it felt slightly intimidating, as in, you kinda like, you know, as if you had to say the right things."

- Toby – Health care assistant, post staff event

Following the joint event, members of Research Net continued to describe the staff-patient collaboration as a positive thing but staff remained cautious and expressed concerns although some members of staff were now more hopeful of a positive impact from the staff-patient collaboration.

Karen, service user member of Research Net and who was interviewed both after the staff and joint event, remained positive:

"I was quite pleased to make a difference, doing the film and spending time with staff, listen to them and hope they would see what we were trying to do, see we were making a difference and not to criticise, I thought it all went really well."

- Karen – service user member of Research Net, post joint event

Kate, a staff nurse who was also interviewed both after the staff and joint event, continued to expressed concerns about the staff-patient collaboration:

"I had the same concerns as before, you know, how to say things in a professional way, because obviously you are aware there are ex-service users or current service users there, so it's putting things forward or saying things in the right way."

- Kate – staff nurse, post joint event

A little further on in her interview, Kate's concerns appeared to alleviate slightly:

"I said it didn't feel right to have service users we had nursed so closely, but I think it was better after this event (joint event), I think there was maybe more understanding, that we are not just sitting in the office just doing nothing and that we have got lots to do, and they became aware of that through the process."

- Kate – staff nurse, post joint event

Another member of staff, Ken, was more positive about the staff patient collaboration.

“I guess the Research Net involvement and the process, I think of as nice, as an ‘us and them’, staff and service user alignment and they would be happy in the whole process, their involvement as well as, watching the videos. You know, service users sitting on a table with a Consultant Psychiatrist and to have a conversation a mile away from a ward round and that may not have happened several years ago, I think that’s great and really positive.”

▪ Ken - psychologist, post joint event

Ken was also hopeful that the staff patient collaboration would bring a positive impact and help break down the staff patient barriers in mental health services.

“I think the attitude towards service users and Research Net separately and as one, I think can change, there have been some negative reactions to service users and Research Net, but this could give them greater respect, which can only be a good thing.”

▪ Ken – psychologist, post joint event

Paul, the ward manager, also felt the staff patient collaboration to be a good thing. In his interview following the joint event he said:

“It was good that we had the opportunity to work closer together and I think together we have worked out what we will be working on in the work stream, not long just the first hour, but the whole admission process and we did that together, it’s good because we will get everyone’s views.”

▪ Paul – ward manager, post joint event

Norman, the facilitator described the staff and patient collaboration in this EBCD project as very much both groups working as a team:

“Well with this particular project I know we had an advantage because they had already been doing co-based production, but the way Research Net had done it was very good, so it wasn’t really a joint event where people would be coming together for the first time, so no “ka pow” like we had at the first EBCD project. I thought it was a very much better way of doing it, much more slow integration and

the joint event, I knew there wasn't multiple concerns for staff and service users meeting each other."

- Norman – facilitator, post joint event

5.5.8. Power imbalance

The final key theme in exploring research objective 1 was the power imbalance that was perceived by the participants throughout the EBCD process; there were sub themes of senior managers and staff, staff and patients, and patients and staff.

There was a difference between the members of staff perceptions of power imbalances and the members of Research Net's perception. Following the staff event, there was a definite feeling from the staff that they had been selected for the EBCD project by senior managers:

"I don't think we volunteered, definitely not collectively; we were made aware that it was going to happen...we were told it was going to happen."

- Toby – Health care assistant, post staff event

This was supported by Paul, the ward manager, who was not sure why the ward he managed was selected to be involved in the EBCD project:

"We were told by the director that it was happening on the ward, weren't really told why, they picked the last one because there were lots of complaints, so it makes you wonder why we were picked. "

- Paul – ward manager, post staff event

Members of Research Net were more concerned with the power imbalances they had seen during their observations on the ward and during the conversations at the staff event concerning how care was delivered on the ward:

"One thing I learnt which took me by surprise is that one of them said, some people instead of sectioning them, they um, say you have to go on the ward, you'll be voluntary, so that gets them on the ward, but when they are on the ward they say that if you try and leave we will section you, that really stood out from all the things that were said."

- Peter – Service user member of Research Net, post staff event

Staff, when discussing the EBCD project, felt that the power had shifted from staff to patients and that the EBCD project was focused on patients rather than an equal balance:

“...it needs a lot more staff input and staff contribution to create, you know, the co-design aspect so far is coming from the side, the side of the patients and not from the side of the nursing staff, the discussion on the day is great, but you need a hell of a lot more than just one chat about it, cos if you going to be the one that either amend it or you know, making our practice more uniform to a template that works better for the patient, then we need to be the ones really designing it more.”

- Toby – healthcare assistant, post staff event

This was supported by another member of staff, Kate, who felt that any redesigning of how services are delivered needs to be done more by the staff than the service users:

“So it shouldn’t be 50:50, the rule shouldn’t be made 50% of what the patients think and 50% of what the nursing staff perceive things to be, because I think it will help us because we will become more aware of how it feels for them to go through the process, but actually I am not sure that the patients will ever understand everything that has to be done from a management point of view, from a government point of view and to fit them all together. I don’t think that’s an easy task. So what I’m saying maybe it should be less patient input and how it feels to them, although we need to keep that in mind, if that makes sense. I think the rules have to work for those of us that are here all the time and know all the pressures.”

- Kate – staff nurse, post staff event

Conversely the members of Research Net were more concerned about what the members of staff thought:

“I was really worried what the staff would think about what we said when we reported what we saw and that they wouldn’t be happy of the things we picked up on the observations, they work on the ward and they say how things are done.”

- Karen – Service user member of Research Net, post staff event

Following the joint event, the ward manager, Paul continued to express his suspicion that they had been 'picked' for the project:

"Yes, I still think they decided that this should happen on my ward, not sure why though, I think we do good work, we look after patients, the patient feedback is good, somebody at the top thinks differently it seems."

- Paul – ward manger, post joint event

Staff also highlighted the power imbalance between staff and patients following the joint event. Ken the psychologist, was concerned that the films could increase the power imbalance between staff and patients, by increasing the divide between them:

"I had anxieties about some of the patients that had been filmed and how the team would respond to them because, knowing those who were involved there is a lot of bad feeling probably in both directions, and if those patients stories were on, people would switch off and things remained unresolved in staff's minds."

- Ken – psychologist, post joint event

Some staff continued to feel that the EBCD process was more focused towards the patients rather than staff. Paul the ward manager said.

"I think EBCD is positive and as I say it works for both sides, patients are important but the staff also have to be considered and their workload, you know if we can trim a little bit that will be helpful. I don't think EBCD has been thought of from a staff perspective, I think it's client focused, which I can understand, but I think, as I said, it's not necessarily all about the patient, it should be about the two parties that are in that relationship."

- Paul – ward manager, post joint event

Ken, the psychologist who had concerns that the films would increase the power imbalance and increase the divide between staff and patients, felt that the process of EBCD and in particular the way staff would work with people they had nursed and were now well, actually reduced the divide:

"As a therapist who works in the ward and in the community, I get to see people get better, there's one person, who is involved in Research Net, at the end of our work, she was going into Research

Net and do stuff, and now she is doing great. I get to see people well, it is something I have that the ward staff don't get much of. But the EBCD event allowed them to see people well, to see them as people not just patients, it was a great thing."

- Ken – psychologist, post joint event

5.5.9. Summary of findings for Research Objective 1

- Adhered to the EBCD toolkit, evidencing EBCD's applicability to a mental health setting
- Due to the intervention being service user led, co-design began earlier in the process than in a traditional EBCD process
- Films were a powerful medium to articulate service user narrative
- Staff sceptical of the EBCD process
- Service users more optimistic that EBCD would improve care
- Staff and service users were anxious about the process of EBCD, but service users found being involved a cathartic process, as it alleviated their anxieties and improved their confidence
- Staff felt there was a power imbalance in the EBCD process, between them and senior managers and also between them and service users, with staff feeling power had shifted to service users

5.6. Research Objective 2

To explore whether such a service-user led co-design intervention can be successfully implemented in this setting

Data to inform research objective 2 was taken from observations of the staff and joint event and also from semi-structured interviews. At the events the author observed and recorded the process of EBCD to enable him to explore whether it was being successfully implemented in this specific mental health setting. The field notes were explored using themes; the themes relevant for research objective 2 will be presented here. For the purpose of clarification, 'successful' implementation is defined as maintaining fidelity to the EBCD model, as defined in Chapter 3, and that each of the steps involved in implementing an EBCD project were able to be implemented in an acute mental health setting.

5.6.1. Field Note observations - time spent in co-design

This section will explore what happened at both events and will present the author's reflections on what was happening, what improvements were planned to be made, and whether the planned improvements were implemented or not.

At the staff event, the members of Research Net had positioned themselves on each table, the author's description of the room was"

There were four round tables in the room with chairs around them, each table had a mix of Research net people (2 on each table) and staff.

For the author this felt different from the traditional EBCD process, as if the co-design part of EBCD was happening earlier in the process. A bit later in the event, the facilitator brought members of Research Net in and asked for their comments following a discussion about how it felt to work on the ward. A member of Research Net, who had recently been a patient on the ward highlighted the good practice she had seen on the ward and said that whilst she was a patient on the ward, she felt the staff worked really hard. The author felt that these comments from a former patient helped launch the EBCD process:

Flo, a member of Research net, said what really shocked her was how hard the staff worked, 'this was well received by the staff', 'feels like the beginning of staff and patients working together. Following Flo's comments, there was lots of agreement in the room, the comments generated a lot of good discussion about the difficulties on the ward, the author reflected that it appeared that the staff felt valued and appreciated by the patients from Research Net.

▪ Field notes, staff event

The facilitator at the staff event then led a discussion around working with Research Net on this project, focusing on working with patient who were well, in contrast with the staffs previous experience of the individuals whilst they were on the ward and mentally unwell. This acknowledgement and discussion gave an understanding to the staff about the people behind the mental illness. The author's reflection on this moment in the overall EBCD process was:

Lots of nods and agreement around the room, following the facilitators comments, it felt as if there was a complete understanding in the room of the ethos of working with EBCD, which up until that point in time of the staff event, hadn't been there.

▪ Field notes, staff event

The presence of Research Net at the staff event felt to the author that the co-design part of EBCD had started earlier than was usual in a traditional EBCD project. This was

evident in the table discussions that occurred around (a) the patients emotional touch points when admitted to a psychiatric ward and (b) which patients should be asked to be interviewed. Each table was a mix of staff and members of Research Net; this led to the tables being able to explore together what the staff thought were the issues with immediate clarification from Research Net, who had lived experience of being admitted. This brought a shared understanding of the issues based on joint experience.

Table 4, highlighted that they wanted an understanding of patient expectation and what was seen as good, suggested a sample of patients who had their first admission and people who had had several admissions, both under section and informally, table 3 wanted to explore how being restrained felt for patients, table 1 wanted to understand the patient experience of queuing (staying on award but not having an actual bed), wanted to understand more about patients experience of ward rounds.

- Field notes, staff event

For the author, this demonstrated an understanding in the room of what they were supposed to be doing and how they would play their part in the co-design process of EBCD.

At the joint event, the co-design part of the process is structured into the events design. However the author felt that there were examples from the event that went further to enhance the process of co-design than the traditional process of an EBCD project. At the commencement of the joint event, all attendees - staff and members of Research Net - came in and sat where they liked. However within five minutes, a staff member of Research Net had rearranged the room and asked that everyone split up and designated who sat where; this meant that there were an equal number of staff and members of Research Net on each of the three tables. The author's reflection on this was that:

This act seemed to break the ice and people began talking to each other, where previously there had been an awkward silence.

The second part of the event that felt for the author to be co-design 'above' the traditional EBCD process occurred during the coffee break when the author observed that the two groups - staff and members of Research Net – did not retreat into their two groups but stayed mixed together and continuing their conversations. The author's reflection on the coffee break were:

Good mixing between staff and members of Research Net in the break, good example was the consultant psychiatrist walking out of the room deep in conversation with a member of Research Net and the films and the issues they were raising. All conversations in the break seemed to be about the films, no one group was isolating itself, no cliques, staff and members of Research Net were mixing freely.

5.6.2. Planned improvements to the service

As described in the field note observations for research objective 1, the final stage in the EBCD process at the joint event was for the room to agree on the issues they wanted to focus on and to identify the work stream or work streams that would develop and implement changes relating to the agreed issues. This process was followed at the appropriate stage of the joint event with the facilitator directing the room to discuss on their tables and identify three areas that they wanted to focus on for the work streams. The facilitator asked the room to vote on the work stream to be taken into the co-design phase of the EBCD process; Flo, a service user member of Research Net suggested that focus on one work stream only as she felt that this would give it more chance of success, this suggestion was supported by Paul the ward manager, who was on the same table as Flo. Karen, a service user member of Research said she would like the work stream to be on admission, Karen, a nurse, agreed with this and said this was the most important part of a patient's experience of a psychiatric ward. This part of the EBCD process enable all participants, service users and staff to have equal input into the direction of the project, no side had more power than the other. The author's reflections of this part of the joint event were:

Room opted to go for the admission work stream, lots of conversations continued after the voting about why this was important, room very keen on focusing on the first hour, which is patients first impression of the ward and their first impression of their admission, the Dr wanted to call it the 'Golden Hour'.

- Field notes, joint event

At the end of the joint event the facilitator set the date for the first work stream meeting and helped the room identify who would participate in the work stream, which were equal numbers of staff and members of Research Net. The facilitator asked for 6 volunteers from the room to begin working on the admission workstream. Service user members of Research Net and members of staff had discussions on their tables and

very quickly, 3 service user members and 3 members of staff volunteered to be involved. The author's reflections on this part of the joint event were:

Group members identified for workstream were, Flo, Karen & Jim from Research Net, Paul, Jim and Laura from the staff, first date set for 15/11/15, individuals volunteered readily, no one seemed reluctant to do so.

- Field notes – joint event

The joint event then closed and people went to lunch together whilst; the working group began conversations about what they wanted to do in the first meeting, this initial discussion was led by Flo, a service user member of Research Net. Following the lunch, staff left and the members of Research Net waited and discussed and reflected on what had happened during the morning. The author's reflections were:

Whole room went to have lunch together, workstream group were working through the agenda for their first meeting, conversations continued over lunch, research Net and staff were all mixed up, not a 'them and us'. Following the lunch, staff drifted off, Research Net hung back to discuss morning, all felt event went really well, the feeling was that the staff were up for the challenge and to work with Research Net to improve how patients experience an admission to the ward.

- Field notes – joint event

5.6.3. Semi-structured interviews

To help address research objective 2, semi-structured interviews were also conducted with nine participants at the staff event and nine participants following the joint event. The interviews were undertaken after the two observations had been completed. The purpose of the interviews was to explore with the participants, both staff, members of Research Net and the facilitator's perception successful implementation of the service user led EBCD intervention in a mental health setting.

The characteristics of the interviewees have been described earlier in Table 5-5.

5.6.4. The successful implementation of a service user led EBCD intervention in a Mental Health setting

Analysis of the interview transcripts led to three key themes emerging in relation to staff and Research Net members' perceptions of the successful implementation of the service user led EBCD intervention. These included:

- Successful EBCD implementation
- Unsuccessful EBCD implementation
- Issues in a Mental Health setting

Table 5-9 will present the sub-themes within these:

Table 5-9 Themes and subthemes: The successful implementation of a service user led EBCD intervention in a Mental Health setting

Themes	Sub themes
Successful EBCD implementation	Following EBCD toolkit Workstreams Following process Skill set required
Unsuccessful EBCD implementation	Deviation from toolkit
Issues in a Mental Health setting	Project management Editing films Time delays Leadership

5.6.5. Successful EBCD implementation

This theme and its sub themes emerged from responses to the interview questions to the staff and members of Research Net about their experience of implementing the EBCD process in a mental health setting. The theme of successful EBCD implementation included sub themes of: following the EBCD toolkit, workstreams, following process and skill set required.

Following responses from both members of Research Net and staff, it seemed that EBCD could be successfully implemented in a mental health setting. Members of Research Net, who were undertaking the intervention, were able to undertake the initial processes in the EBCD stages (the observations and interviews of staff):

“Yeah, there was usually a Research Net staff member and two other members of Research Net doing the observations, we did a shift, either the morning or late shift, to get a good long period of

observing, we also used two of us to do the interviews, one to ask questions and one to record.”

- Nigel – staff member of Research Net, post staff event

Karen, one of the service user members of Research Net, was also able to describe how she was involved in following the EBCD toolkit, by undertaking the observations and interviews.

“I did the observations and the interviews, which I found really interesting, I interviewed a psychologist and a nurse and observed a whole morning shift. I found the interviews quite easy when I asked the questions and I also spent one interview taking notes, so I had a mixture.”

- Karen – service user member of Research Net, post staff event

Norman, the facilitator, also reflected on how he felt the joint event had gone and he compared it to other EBCD projects he had been involved in:

“I had a run of them as well, so I had another event just before, but I think just prior to that I had done training with the King’s Fund, what I realised was that I was getting much clearer after god knows how many years – 4 years of EBCD, about what it is, about the relationships between the films, extracting the touchpoints, prototyping, so I felt quite in a good space because I felt, no, there is a lot here we could take up, we just need to drive forward, we need to go away with at least one action point, you know that’s all we need to do, there was a process, it felt structured, we got to an action point following the films and agreed the workstreams.”

- Norman – facilitator, post joint event

Interviews following the joint event described how the workstream had been agreed, group members appointed and dates set. Karen, one of the service user members of Research Net described how the workstream had been going:

“We have had meetings back on the ward with Paul (ward manager) after the joint event, so we have decided we are going to improve the

admissions process, we have a number of meetings and they are going really well, it felt like the staff really were looking to us for help, asking for advice, we are designing the information leaflet for when you are admitted to the ward and the questions that are asked and how they are asked. Because I know myself from when I was an in-patient, there were a lot of things I would have liked changed, simple things like communication, which we are doing, because you know I was left sitting there for quite a while without anyone talking to me and that can be quite lonely.”

- Karen – service user member of Research Net, post joint event

Paul, the ward manager, agreed with Karen in his description of how the workstream was progressing:

“The meetings have been fairly good, we were able to discuss where we are going, Laura came down, Laura is leading on it, she brought down some of the paper work that we actually currently use, and she gave everyone copies and we all spent the time looking at them, saying whether there are things that we can expand on or reduce or change in any way and get feedback from Research net, we need everyone’s opinions.”

- Paul – ward manager, post joint event

5.6.6. Unsuccessful EBCD Implementation

During the interviews, it became apparent that there was one aspect of the EBCD model that the members of Research Net did not adhere too; they did not hold a patient event to gather patient perspective on their emotional ‘touch points’ when they are on a psychiatric ward. Rather, they chose to directly recruit service users to be filmed individually as to their experiences.

Norman, the facilitator, and founder of the group Research Net, reflected that this was a difference in a mental health setting, as service users found the process of seeing their stories on films as traumatic, so using Research Net to tell their stories was a more effective way to undertake the EBCD process in a mental health setting:

“All interviews are with Research Net, so no need for a patient event, as Research Net know why we are doing this and what the purpose of the interviews are. We did recruit some service users from outside Research Net to interview and they had a hell of a shock, this is why

we use Research Net, as they meet regularly and they have the support, but it confirmed to me, that in mental health, people are so shocked by seeing their own story on film, they have really big reactions to their own films.”

- Norman – facilitator, post joint event

Ken, the psychologist, reflected in his interview that there was a part of the day of the joint event that did not for him feel like it was co-designed.

“There was an element of the event day, where I felt that it did slightly start to loss the co-design bit, a little, towards the end of the event, As kind of the main themes were getting homed in on, I felt it wasn’t becoming quite so co-created, there was some views in the room that really liked an idea and were kinda running with it. I wasn’t sure how useful the vote was, everyone was getting swept along with a tide of enthusiasm. This might be just my opinion, but it felt like it was being a bit compere led.”

- Ken – psychologist, post joint event

5.6.7. Issues in a Mental Health setting

There were other specific issues that became apparent during the interviews in relation to implementing EBCD in a mental health setting which needed to be considered and thought through. These issues were mainly raised by Norman, the facilitator and Nigel, the staff member of Research Net:

“Is there something particular to mental health? I think there might be as I think it is the least practical health care setting, in other words, sad to say, I think too much empathy in the leaders is going to make this not work because you have to push people. Do you see my point, it was not taking that initial ‘I can’t do this’ as an answer. Whereas I worry that too, that very empathetic mental health type people may not push it and perhaps almost reinforce the disability that people come to our services with.”

- Norman – facilitator, post staff event

There was a concern about the amount of time the project seemed to have taken.

Nigel, the staff member of Research Net, highlighted there was an issue with time delays in the project. He described how they were implementing the EBCD project and talked of how much time everything took:

"We have done a sort of timeline schedule, so we've set ourselves some deadlines, but it is all taking a long time. We were conscious that unless we do, that it's just flopping around, as I said the other day, it's June, then it's July or it could be August, it doesn't help to manage a project by just having it open ended."

- Nigel – staff member of Research Net, post staff event

Paul, the ward manager, continued to express concerns about how long the project had taken when he was interviewed following the joint event.

"I think that the time it has taken from start to finish hasn't helped because some staff I had were there when we first started but weren't there when we finished, so it would have been nice to have it condensed a bit more, it's felt like it's been a long process and it has felt a bit lost at times. It does feel like we are back on track, now we are meeting every two weeks for the workstreams, it feels better."

- Paul – ward manager, post joint event

Norman, the facilitator shared Paul's concerns about the time delays and the impact this may have had on the joint event. There was a concern that there may have been a different staff group in the joint event from the staff event and that this may have impacted on success of the project.

"There had been a long delay from the February point, when we tried to set it up, I don't know what was going on, the amount of delays that they had built in had been annoying Research Net, maybe the energy had gone from it, there might be different staff, you know what these places are like with staff turnover – maybe its different people and I was thinking I might look round the room and I might not recognise people, so the delay had worried me."

- Norman – facilitator, post joint event

Norman, the facilitator, reflected that to successfully implement an EBCD intervention in a mental health setting and prevent the time delays a certain skill set is required and highlighted the need to have project management skills.

“The staff members of Research Net are leading the project, but they don’t have project manager skill set, deep down, I also think, it’s a personal style thing about project management. For EBCD you need a hassle board, with timetables, and yes, we can’t let that one slip, there isn’t endless time, we have got to get anxious, “

- Norman – facilitator, post staff event

As Norman, the facilitator, had been involved in a number of EBCD projects in a mental health setting, the author asked him for his reflections as to how he felt EBCD works in a mental health setting, Norman broke this down into a number of areas, his first point was that he felt EBCD was vital in addressing what he felt was wrong in the way mental health services were delivered, by services being designed by how the clinical intervention happened rather than how it feels to the patient:

“I think EBCD is a massive corrective for what is wrong at the heart of mental health on 2 levels: one we don’t use basic design principals to designing services, I think this thing of the aesthetics of care, how a service feels I think is not an add on to the primary tasks, I think it is the primary task. So the reason I think it is a corrective I think we try and meet service users emotional experience with our own particular professions, an art therapist will meet them with therapy, a doctor will meet them with medicines you know etc., etc. I think it is a mistake, I think EBCD is the corrective in this.”

- Norman – facilitator, post joint event

Norman then described his next point, as to why designing services to how a clinical intervention is delivered is fundamentally the wrong way to deliver services in mental health, as it perpetuates service-users experience of mental illness rather than alleviating it:

“...so what we are talking about is this that there may be a small medical element there may be a small therapy element but the human experience , we are reading ordinary fear responses as pathological responses because that is our specialism and I think we are reinforcing a kind of illness state with people whereas when you look at it from the design principal you think, well I would feel like that, I would feel terrified coming on the ward if you take up these things with just ordinary human communication, actually quite a lot of the apparent medial psychological therapy needs , they go away.”

- Norman – facilitator, post joint event

5.6.8. Work stream implementation

As highlighted earlier in the Chapter, in section 5.4.1, the joint event had identified 4 key themes that came from the discussions prompted by the service user films about receiving care on a psychiatric ward, these were;

1. Admissions
2. Activities
3. Routine
4. Paperwork

The field note observations for this research objective identified that the staff and service users had decided to focus on the theme of admission to take forward into the 5th stage of the EBCD process.

At the joint service user and staff event, the membership of the workstream was selected; it included 3 service user members of Research Net and 3 members of staff from the ward, including the ward manager. The date for the first workstream meeting was set at the joint staff and service user event and the group then met at this first meeting which was held in a community mental health team base near the psychiatric ward, the author observed this initial meeting and also the second meeting. At this initial meeting dates for four further meetings were booked; the same members of Research Net and staff attended the subsequent meetings. Flo, a service user member of Research Net, started the discussion about the admission process and what was important for service users, Laura, a nurse asked the members of Research Net for their experiences of being admitted to a psychiatric ward. Karen, a service user

member of Research Net, said that when she was admitted to the ward, it was a very frightening experience, as she didn't know what was happening, who people were or whether she was ever going to get out of the ward. Jim, a member of staff suggested that the group look at the information that it is given to service users, the group agreed this was a good idea and Jim said he would send it all to everyone before the next meeting.

At the second workstream meeting - Karen began the discussion on what could be improved, Flo said it would be better if all the information was in one place, Karen said a leaflet would be helpful - the workstream then decided to develop a leaflet that would focus on the information that a new service user received. Working together the staff and members of Research Net designed the service user information leaflet. The leaflet was A4 size folded into three sections, with a picture of the ward and the name of the ward, together with the ward's contact details on the front. The leaflet was in the corporate colours of the trust, yellow and blue and had the trusts' logo on each page. The inside of the leaflet detailed the new agreed content. The inner pages of the leaflet detailed; what happened on a psychiatric ward; who the staff were; what their roles were; the layout of the ward and what the processes of the ward were; it also had a section that detailed the type of questions service users would be asked, and detailed why they were being asked these. Once the leaflet had been designed, it was then introduced and implemented on the ward in April, 2016, when it started to be given to service users on admission to the ward. This leaflet was the co-designed change following the EBCD quality improvement process.

Prior to this no information was given to service users, all the information was given verbally to service users by the nurse that admitted them to the ward. The co-design workstream sat together during the workstream meetings and listed all the information staff required from service users and then listed all the questions that the members of Research Net had when they were admitted to a ward, what they felt they needed to know and the things that they weren't told. The co-design workstream, led by Flo and Karen, service user members of Research Net, then outlined the information they wanted on the leaflet, once they had agreed what they wanted, Paul, the ward manager took the leaflet the associate director of mental health services responsible for the ward for approval, Jim the member of staff and Karen then worked with the trusts' communication department to design the leaflet, once that was agreed it was sent off to be printed and was then started being given to service users in April 2016, now all service users are given this leaflet.

5.6.9. Summary of finding for research objective 2

- EBCD can be successfully implemented in a mental health setting, although there are specific issues relating to a mental health setting
- EBCD can be led by a service user group
- Co-design decision of workstream is key
- No service user event, which was a deviation from the traditional EBCD process, due to traumatic nature of filming for mental health service users
- Specific issues for mental health setting; project management and leadership skills required
- Concerns raised as to how much time the project was taking

5.7. Research Objective 3

To measure the impact of the service-user led co-design intervention by comparing the ward atmosphere before and after its implementation and identifying any changes

The experience of staff and patients on the ward selected for the EBCD intervention was measured using the ward atmosphere scale (WAS), using the methodology outlined in Chapter 4, sections 4.6.1 and 4.8.6. The WAS is a 100-item questionnaire, set out in a true/false format. The 100 items map onto 10 sub scales, each of which falls into one of three dimensions of the treatment environment, relationship dimension; personal growth dimension and system maintenance dimension:

1. The Relationship dimension, which includes the Involvement and the Support & Spontaneity sub-scales.
2. The Personal Growth dimension, which includes the Autonomy, Practical Orientation, Personal Problem Orientation and Anger & Aggression sub-scales.
3. The system Maintenance dimension, which includes the Order & Organisation, Programme Clarity and Staff Control sub-scales.

There is a different meaning for each of the subscales, some favour a higher score for a positive result, others favour a lower score for a positive result. These will now be highlighted.

5.7.1. Ward Atmosphere Scale

Relationship Dimensions

1. Involvement (I) how active and energetic service users are in the program. A higher score in this sub scale is positive.

2. Support (S) how much service users help and support each other and how supportive the staff is toward service users. A higher score in this sub scale is positive.
3. Spontaneity (Sp) how much the program encourages the open expression of feelings by service users and staff. A higher score in this sub scale is positive.

Personal Growth Dimensions

4. Autonomy (A) how self-sufficient and independent service users are in making decisions and how much they are encouraged to take leadership in the program. A higher score in this sub scale is positive.
5. Practical Orientation (PO) the extent to which service users learn social and work skills and are prepared for discharge from the program. A higher score in this sub scale is positive.
6. Personal Problems Orientation (PPO) the extent to which service users seek to understand their feelings and personal problems. A higher score in this subscale is positive.
7. Anger and Aggression (AA) how much service users argue with other service users and staff, become openly angry, and display other aggressive behaviour. A lower score in this subscale is positive.

System Maintenance Dimensions

8. Order and Organization (OO) how important order and organization are in the programme. A higher score in this sub scale is positive.
9. Program Clarity (PC) the extent to which service users know what to expect in their day to-day routine and the explicitness of program rules and procedures. A higher score in this sub scale is positive.
10. Staff Control (SC) the extent to which the staff use measures to keep service users under necessary control. A lower score in this sub scale is positive.

The service-user and staff scores both pre and post intervention will now be presented, this will also be presented as a graph to aid comparison. Service-user scores pre and post the EBCD intervention are presented in Table 5-10 and the graph is in Figure 5-1. Staff scores pre and post the EBCD intervention are presented in Table 5-11 and the accompanying graph is presented in Figure 5-2. The data in tables 5-10 and 5-11 represent a group mean score of the service users and staff that completed the survey; 14 service users completed the survey pre intervention and 15 completed it post intervention; 14 staff completed the survey pre intervention and 14 completed it post intervention.

5.7.2. Pre intervention scores, November 2014; Post intervention scores, June 2016.

Table 5-10 Ward Atmosphere Scale – Service User group mean standard scores (Service User no. 14 - pre EBCD; Service User no. 15 – post EBCD)

Subscale item		Score Pre-EBCD		Score Post-EBCD	
		Raw	Standard	Raw	Standard
Involvement	I	3	28	6.5	51
Support	S	4	27	7.5	57
Spontaneity	SP	4	37	6.5	47
Autonomy	A	3.5	31	5	45
Practical Orientation	PO	3	26	6.5	53
Personal Problem Orientation	PPO	5	48	5	48
Anger and Aggression	AA	5.5	53	4.5	46
Order and Organisation	OO	3.5	23	8	60
Programme Clarity	PC	3.5	21	7.5	60
Staff Control	SC	6	50	3	28

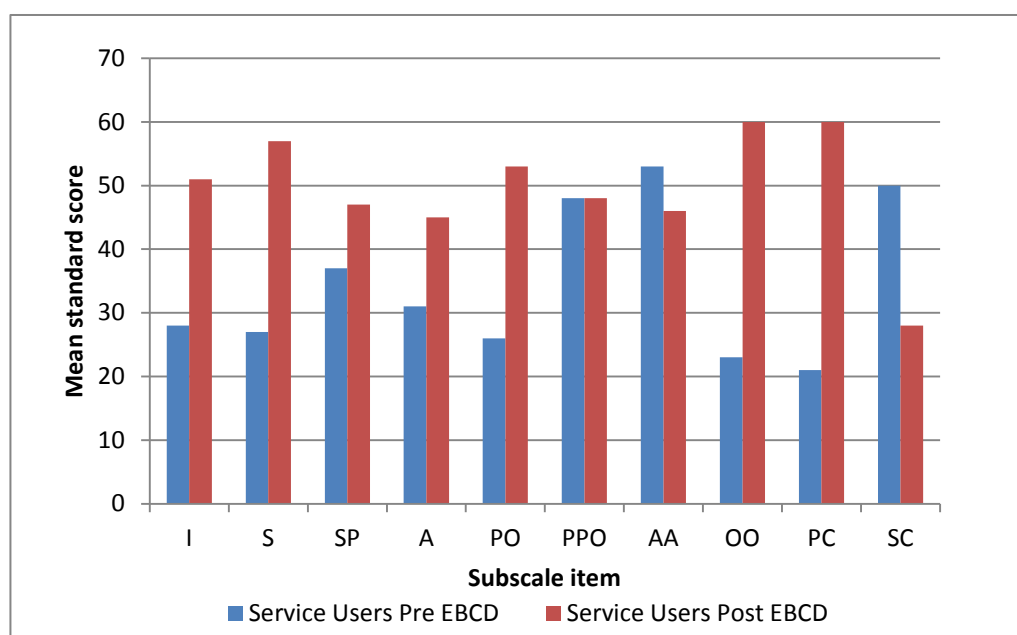


Figure 5-1 Service user group mean standard scores, pre & post intervention

The service-user scores demonstrate an improvement for the experience for service users in 9 out of the 10 subscales, following the EBCD intervention; involvement, support, spontaneity, autonomy, practical orientation, anger and aggression, order and organisation, programme clarity and staff control. There is no change in one sub scale, personal problem orientation.

Table 5-11 Ward Atmosphere Scale – Staff group mean scores (Staff No. 14 - pre EBCD; Staff no. 14 – post EBCD)

Subscale item		Score Pre-EBCD		Score Post-EBCD	
		Raw	Standard	Raw	Standard
Involvement	I	4	34	5	40
Support	S	5.5	31	7	45
Spontaneity	SP	7	55	7.5	59
Autonomy	A	4.5	41	5.5	47
Practical Orientation	PO	6	48	7	55
Personal Problem Orientation	PPO	6	50	5.5	47
Anger and Aggression	AA	6.5	52	5.5	47
Order and Organisation	OO	5	41	6.5	50
Programme Clarity	PC	6	38	8	55
Staff Control	SC	1.5	34	1	31

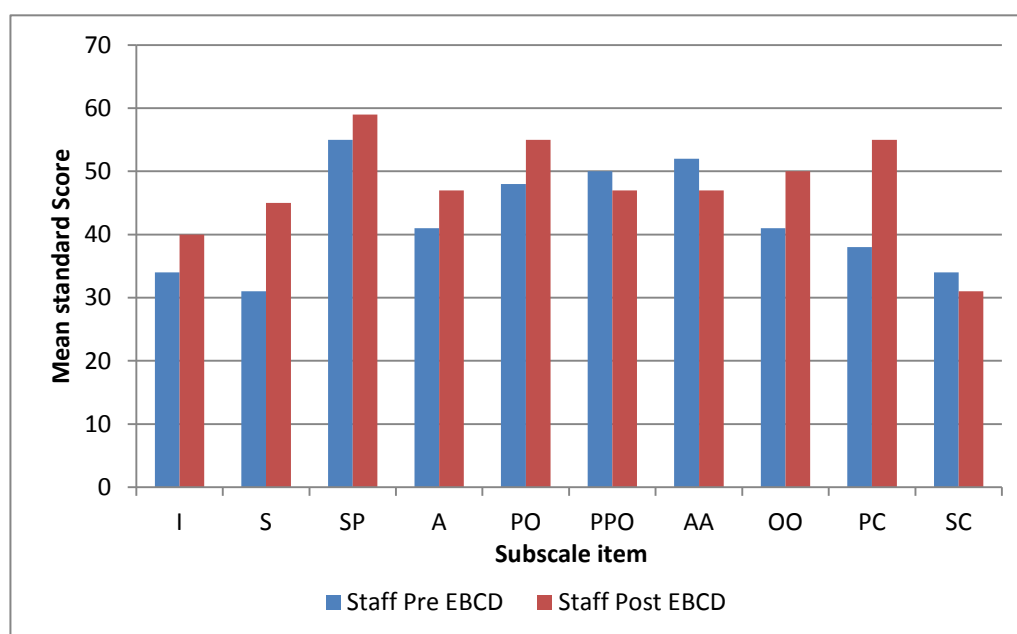


Figure 5-2 Staff group mean standard scores, pre & post intervention

The staff scores demonstrate an improvement in scores in 9 out of the 10 subscales, following the EBCD intervention; involvement, support, spontaneity, autonomy, practical orientation, anger and aggression, order and organisation, programme clarity and staff control. One sub scale, personal problem orientation, got worse.

5.7.3. Statistical significance

Statistical significance for the pre and post EBCD intervention for both service-user scores and staff scores, was calculated using a standard unpaired t-test. This will now be presented for both the service user scores, Table 5-12, Table 5-13 will present the data supporting statistical significance or not. The staff scores are presented in Table

5-14, the data supporting statistical significance or not will be presented in Table 5-15. Comparisons, for both the service-user and the staff scores will be made for service users and staff, for each of the 10 sub scales. As comparison will be made for each of the 10 sub scales of the WAS, this increases the chance of achieving some statistical significance in some or all of the sub scales, therefore to compensate for this, the measure of P that signifies statistical will be taken as $P = 0.05$, as this is a 10th of the standard $P = 0.5$ to demonstrate statistical significance.

Table 5-12 service-user scores P value and statistical significance

	P value	Statistically significant
Involvement	0.0005	Extremely significant
Support	0.0003	Extremely significant
Spontaneity	0.0099	Very significant
Autonomy	0.0005	Extremely significant
Practical Orientation	0.0005	Extremely significant
Personal Problem Orientation	0.98	Not significant
Anger and Aggression	0.06	Not quite significant
Order and Organisation	0.0001	Extremely significant
Programme Clarity	0.0001	Extremely significant
Staff Control	0.0003	Extremely significant

Table 5-13 data supporting statistical significance for service-users scores. Confidence interval (CI) is expressed as group 1 mean subtracted from group 2 mean. Error is expressed as the standard error of the difference.

Parameter	CI	95% CI Range	t value	Error
Involvement	-15.90	-24.13 to -7.67	3.9618	4.013
Support	-15.38	-23.09 to -7.67	4.0936	3.757
Spontaneity	-11.06	-19.24 to -2.89	2.7769	3.984
Autonomy	-9.43	-15.86 to -2.99	3.0061	3.137
Practical Orientation	-16.84	-25.51 to -8.51	3.9841	4.226
Personal Problem Orientation	-0.07	-7.06 to 6.92	0.0210	3.407
Anger and Aggression	4.88	-0.26 to 10.03	1.9463	2.508
Order and Organisation	-20.05	-29.37 to -10.73	4.4123	4.544
Programme Clarity	-17.28	-25.09 to -9.46	4.5350	3.810
Staff Control	16.12	8.13 to 24.11	4.1401	3.893

Of the 9 subscales that demonstrated an improvement for service user experience following the EBCD intervention, 7 of the subscales demonstrated that the improvement in the score was extremely statistically significant; involvement, support, autonomy, practical orientation, order and organisation, programme clarity and staff control. 1 of the subscales, spontaneity was a very significant statistical improvement. Although there was an improvement in the anger and aggression subscale, it was not

quite statistically significant and the final subscale personal problem orientation did not demonstrate an improvement and is therefore not statistically significant.

Table 5-14 Staff scores P value and statistical significance

Parameter	P value	Statistically significant
Involvement	0.203	Not significant
Support	0.04	Not Significant
Spontaneity	0.125	Not significant
Autonomy	0.1174	Not significant
Practical Orientation	0.1487	Not significant
Personal Problem Orientation	0.7977	Not significant
Anger and Aggression	0.0271	Not Significant
Order and Organisation	0.1809	Not significant
Programme Clarity	0.0622	Not significant
Staff Control	0.2	Not significant

Table 5-15 data supporting statistical significance for staff scores. Confidence interval (CI) is expressed as group 1 mean subtracted from group 2 mean. Error is expressed as the standard error of the difference.

Parameter	CI	95% CI Range	t value	Error
Involvement	-4.00	-10.30 to 2.30	1.3059	3.063
Support	-6.97	-13.24 to -0.33	2.1609	3.140
Spontaneity	-3.14	-7.22 to 0.94	1.5826	1.986
Autonomy	-3.21	-7.29 to 0.87	1.16195	1.985
Practical Orientation	-5.14	-12.15 to 1.96	1.4882	3.456
Personal Problem Orientation	-0.57	-5.11 to 3.97	0.2589	2.207
Anger and Aggression	4.57	0.56 to 8.58	2.3425	1.952
Order and Organisation	-6.57	-16.40 to 3.25	1.3749	4.779
Programme Clarity	-8.57	-17.61 to 0.47	1.9486	4.399
Staff Control	2.57	-1.80 to 6.94	1.2103	2.125

The staff scores also demonstrated an improvement, following the EBCD intervention, 9 out of the 10 subscales; . All nine subscales; involvement, support, spontaneity, autonomy, practical orientation, anger & aggression, order and organisation, programme clarity and staff control. Although the subscales did show an improvement, the improvement was not statistically significant. The final sub scale, personal problem orientation, which got worse, was also not statistically significant.

5.7.4. Summary of finding for research objective 3

- Service users experienced an extremely statistically difference in a positive way about their experience of receiving care on the ward

- Staff experience no difference in their experience of delivering care on the ward

5.8. Research Objective 4

To explore the role and impact of the service-user led group in the implementation of EBCD.

5.8.1. Semi-structured interviews

To help address research objective 4, semi-structured interviews were conducted with 9 participants at the staff event and 9 participants following the joint event. The interviews were undertaken after the two observations had been completed. The purpose of the interviews was to explore with the participants, both staff, members of Research Net and the facilitator's, their perception of the role and impact of the service-user lead group, Research Net in the implementation of EBCD in a mental health setting. The characteristics of the interviewees have been described earlier in this Chapter.

Analysis of the interview transcripts led to two key themes emerging in relation to staff and Research Net members' perceptions of the role and impact in the implementation of EBCD intervention. Table 5.15 will present the sub-themes within these, these included:

- Benefits of using Research Net
- Concerns of using Research Net

Table 5-16 Sub-themes within the service user led EBCD project

Themes	Sub themes
Benefits of using Research Net	Leading research Safer for mental health patients Breaking down barriers
Concerns of using Research Net	Process of EBCD Issues with using Research Net Critical patient

5.8.2. Benefits of using Research Net

The first theme that was identified in the interviews with staff, members of Research Net and the facilitator was the benefit of using Research Net, a service user group in the implementation of EBCD in this setting; the sub themes of this first theme, were leading research, safer for patients and breaking down barriers. These sub themes will now be explored.

Norman, the facilitator, who had run other EBCD projects in mental health setting, was clear of the benefits of using Research Net and highlighted the aspect of Research Net leading the research, and described how, in this project Research Net took on all aspects of the EBCD intervention:

“Now Research Net go from the start, they edit the interviews they edit the films they lead, do you remember we had Research Net on each table, they lead, we always do that now so they would also lead the design stream so we have been calling them lived experience designers – LEDs – lighting the ways.”

- Norman – facilitator, post joint event

This view was also supported by Nigel, one of the staff members of the Research Net group, who also thought there was huge benefits to having Research Net actually leading the EBCD project:

“Oh a huge value because I think we all of us really own process cos the group clearly feel it’s not just tokenistic they feel this is their project, you know, it’s not just mine and my colleague’s you know, it’s, they are urm taking responsibility you know and there is much more of an ownership yeah, in this.”

- Nigel – Staff member of Research Net, post staff event

Norman also discussed how he felt that there were key leadership skills required to implement an EBCD quality improvement project, and that there was in advantage is using a group like Research Net, as the people come from a variety of backgrounds, and have a different skill set to health clinicians.

“There are some crucial skills for Research Net to learn in that but also some people in research net, we have one lady who is leading a really complicated one with families – she use to manage a factory, so she would be brilliant at that, and that’s been the benefit of the group.”

- Norman – facilitator, post joint event

Norman, the facilitator, continued to relay his views about the benefits of Research Net leading the EBCD project. He felt that having Research Net gave the project validity in the eyes of the staff, and that this started the co design part of the process earlier:

“I think the fact that what this ward showed us, and this Research Net group showed us was that that if they really owned the project they seemed to, they seemed to have credibility to the whole thing for staff, because they can’t pigeonhole patients as patients, I think they started to have some relationship with the ward staff already so there was the seeds of co-production happening already so there wasn’t a ‘them and us’ type of processes”

- Norman – facilitator, post joint event

Ken the psychologist felt that using Research Net, allowed the staff to see the members of Research Net as people first rather than psychiatric patients.

“EBCD allows staff to see well, which is something they don’t usually get to do. Working on the ward and in the community, like I do, means I see that a lot, but the ward staff don’t get so much of”

- Ken – Psychologist, post joint event

Another benefit that was highlighted during the interviews was that the use of Research Net helped to break down the barriers between staff and patients. Ken the psychologist described it thus:

“I think it does break down a lot of the barriers that we would have, that services are normally constrained by in their development, and research net don’t feel tokenistic to me, research net have been around in the trust for a number of years and kinda established I suppose which gives them validity, quite rightly. I think their role is vital and with it being a kinda valid group, of skilled and experienced people that they add a whole layer that you would not have otherwise.”

- Ken –psychologist, post joint event

Norman, the facilitator, also described a very particular benefit of using a service user group like Research Net, in a mental health setting, as he felt that this was safer for patients who use the service, so rather than using patients to tell their stories, use members of Research Net to tell their stories, as they have an already set up support group:

“I think it is essential for mental health, because, I think. We sampled outside research net for the carers EBCD group, we videoed a family and on the day they were going that’s fantastic and we have films of them saying it’s good to unburden yourself. That wrecked that family for a week and it was very dangerous. My argument is that’s because you don’t see the blow back till afterwards but I think that this idea of research net guys perhaps have.... they insist that anyone that makes a film has to keep coming back to a support group.”

- Norman – facilitator, post staff event

5.8.3. Concerns of using Research Net

During the interviews there were a small number of concerns from staff about using Research Net in the EBCD project; staff were uncertain about Research Net being involved in the actual stages of the EBCD process, particularly the observing and the interviewing, as they felt Research Net wouldn’t be unbiased:

“We spoke to each other and everyone said, when we talked about it that it would have been better if they weren’t anything to do with the ward...., the people observing and interviewing the staff, as they were actually seeing the process with a completely unbiased eye , you know , and so, that they can see more.”

- Toby – Health Care Assistant, post staff event

Norman, the facilitator of both events, reflected that he felt that there was a concern from staff that using Research Net to lead the EBCD project was intimidating for the staff group and that this might alter the outcome.

“The trust wanted Research Net there, but they were a bit alarmed when I said they would be leading because they thought that might scare the staff who were there, as you see there is a pattern here (laughs)...mustn’t scare the staff”

- Norman – facilitator, post staff event

Another member of staff, Ken, the psychologist also highlighted a potential issue of using Research Net, he felt that if you used a service user from the ward that was critical of the ward whilst they were on the ward, the staff may not listen to their story:

“Some of the patients there are involved as part of the research net group and were going to be on the video, were always complaining

on the ward, so actually for that person's story staff would switch off when listening as things are, remain unsolved in staff's minds, the films wouldn't have an impact."

- Ken – psychologist, post joint event

5.8.4. Summary of findings for research objective 4

- Safer for mental health service users
- Service users have a different skill set to clinicians, better for EBCD
- Begins to break down 'them and us' barriers, staff see service users as people
- Staff expressed concerns about working alongside service users, mainly around confidentiality

5.9. Summary

This mixed method study has set out to answer four research questions in relation to the impact of a service user led EBCD QI intervention on an acute psychiatric ward. The study had presented the results from the seven phases which used a qualitative WAS survey, ethnographic observation and field notes and semi structured interviews to answer the four research objectives.

The first research objective used ethnographic observations and field notes of two key events in the EBCD process, the staff event and the joint staff and service user event, it also used semi structured interviews of eighteen (n=18) staff and service users following both events. The data showed that EBCD was applicable in a mental health setting and that staff and service users were both anxious about the process but that - whilst service users found that being involved was a cathartic process for them - staff highlighted a perceived power imbalance between them and service users.

Research objective two again used ethnographic observations and field notes of the two key events and semi structured interviews of eighteen (n=18) following both events. The data showed that service users could lead an EBCD project and that because they were leading co-design began earlier in the process than in traditional EBCD. Particular issues were highlighted in a mental health setting, specifically around the traumatic nature of filming mental health service users' narratives, and there was a concern about how much time the process took.

Research objective 3 used the WAS survey to ascertain the possible impact that EBCD had on staff and service users experience of giving and receiving care on the ward. Fourteen staff (n=14) and fourteen service users (n=14) completed the survey pre the EBCD intervention and fourteen staff (n=14) and fifteen service users (n=15)

completed the survey post the intervention. The key finding was that there was an extremely statistically significant improvement for service users in their experience of receiving care on the ward; however the staff experience did not change.

The final research objective used semi structured interviews with eighteen (n=18) people, both staff and service users following both key events. The data showed that there were benefits of a service user group leading an EBCD project, it was safer for mental health service users, due to the traumatic impact of filming. EBCD helped break down the 'them and us' barriers, service users were seen as people, although staff highlighted concerns about confidentiality when working alongside service users.

This chapter has presented the results from the seven phases of the study and used the data to address the four key research questions. Chapter 6 will discuss the results and provide further exploration of the findings.

Chapter 6

Discussion

6.1. Introduction

The previous chapter presented the findings from this multiple methods study to explore the effectiveness of a service user led EBCD, quality improvement intervention in a mental health setting. This chapter will consider the study findings in the context of the wider evidence of the exploration of the effectiveness of EBCD, as a service user led quality improvement intervention in a mental health setting (as highlighted in the background chapter, Chapter 1 and Chapter 2, the literature review) and will also highlight the study's original contribution to the existing knowledge of a service user led EBCD quality improvement intervention in a mental health setting. The findings are then interpreted in the context of relevant theoretical and empirical literature to provide an explanatory framework for the key findings. The strengths and weaknesses will then be discussed together with implications for future practice and research.

6.2. Summary of key findings of this research

In this study, a service user-led research group called Research Net led an EBCD quality improvement intervention on a mental health admission ward. The study found that EBCD could be successfully implemented in an acute psychiatric in-patient ward and that leadership from a service user group was positive both in terms of the EBCD process and the experiences of members of the service user group themselves. However, staff engagement about being involved in such co-design process is a key factor that needs to be carefully considered. The key findings to successful implementation included issues relating to fidelity of implementation, the radical nature of service-user led design, staff engagement, the role of film and visualising patient experience and reflections on my role as researcher. Table 6-1 provides a summary of the key findings.

Table 6-1 key findings of the results from this study

Fidelity of implementation	Service user led design	Staff engagement	The role of film	My role as researcher
Research Net did not hold a service users event, but directly recruited service users. This was acknowledged and recognised; the reflection was this was due to mental health service users finding seeing their stories on film very traumatic.	Service users leading meant services were designed for how they were experienced by service users Co-design began earlier in the EBCD process The patients on the ward experienced a significant improvement in how the ward felt to them	Staff felt process needed more staff input Staff felt they had been 'picked' for the EBCD project Staff found the process of EBCD uncomfortable and unsettling Staff on the ward did not experience an improvement in how the ward felt to them	Films identified where the issues were The experience of being filmed is traumatising for mental health service users; a support group was required Making the films was a positive experience for the members of Research Net	Builds up a trusting relationship between researcher and subject of research Improved the likelihood of success of the QI intervention Potential for researcher to become biased towards subject of research

6.3. Findings in relation to the literature review

It is important to understand how the findings from this study relate to the existing evidence on a service user led EBCD quality improvement interventions in mental health settings. Do the study findings fit with the current evidence? Are there any contradictions to the existing evidence? How does this study extend and deepen the evidence base on the nature and impact of a service user led EBCD quality improvement intervention in a mental health setting?

The literature review for this study found ten qualitative papers that implemented EBCD as a QI intervention in a non-mental health setting and eight qualitative papers that implemented EBCD in a mental health setting. It revealed a number of key themes:

- The use of films is key
- Co-design is a crucial part of EBCD
- May not be representative of all service users views
- None of the EBCD projects were led by a service user group
- EBCD can be implemented in a mental health setting
- Specific adaptations required to implement EBCD in a mental health setting
- Consideration needs to be given to support service users through the intervention
- Different stakeholders had different rationale for involvement
- Limited evidence that EBCD improves outcomes for patients
- EBCD takes a lot of time to do

The majority of the studies were descriptive in nature and described the implementation of EBCD in a health care setting; only one study had implemented EBCD on a psychiatric ward. However, the review of the evidence indicated that EBCD as a QI intervention can be implemented in a mental health setting but specific adaptations are required, particularly around supporting service users through the process and that these important findings are substantiated within this study. The observational data in my study (Phase 2 & Phase 4) confirms that EBCD can be implemented in a mental health setting. The semi structured interviews (Phase 3 & Phase 5) indicated a wide range of perspectives on successful implementation of EBCD in a mental health setting, the specific adaptations required and how the process meant different things for different stakeholders.

In terms of understanding whether EBCD can be implemented in a mental health setting, this study therefore corroborates the findings of earlier studies. Whilst the studies were largely descriptive in nature, they did conclude that EBCD could be implemented in a mental health setting (Hyde & Davies, 2004; Cooper et al, 2015;

Larkin et al, 2015; Murphy et al, 2015; Springham & Robert, 2015; Wright et al, 2015; Mulvale et al, 2016). The existing literature concluded that the EBCD process allowed for meaningful mental health service user involvement.

Also evident in the previous studies was that whilst EBCD could be implemented in a mental setting, there were specific adaptations that were required to do this (Cooper et al, 2015 and Larkin et al, 2015). These adaptations focused around support for mental health service users through the EBCD process; Cooper et al (2015) highlighted that specific consideration was required around the filming of mental health service users' experiences.

Studies highlighted that co-design was key in EBCD (Hyde and Davies, 2004) and that the films of patients' stories were also a crucial aspect of EBCD (Donetto et al, 2014). However, studies also concluded that 'co-design' carried different meanings to the stakeholders involved in the EBCD process (Bowen et al, 2013 and Vennik et al, 2015). Studies also warned that some participants did not feel EBCD represented good value in terms of resources, time and money. (Bowen et al, 2013). Only one study in a mental health setting demonstrated that outcomes were improved for service users, in terms of a reduction in complaints on the unit (Springham and Robert, 2015).

There is consistency within and throughout my study and earlier studies in relation to finding that EBCD can be implemented in a mental health setting but that specific adaptations were required, particularly around the filming of service users experience, and that there were different meanings for the different stakeholders involved. What this study adds is an in-depth understanding of the successful implementation of EBCD in a mental health setting and the content of the adaptations required to do this. This study also adds a greater understanding as to how being involved in an EBCD project meant different things to the service users and staff involved as well as adding to the knowledge base that EBCD improves outcomes for service users, but not necessarily for staff. This study has been able to substantiate and extend our understanding of the implementation of EBCD in a mental health setting.

6.4. Interpretation of findings

The findings in this study indicate a number of factors that contributed to the implementation of EBCD as a QI intervention in a mental health setting. These are presented diagrammatically in Figure 6-1.

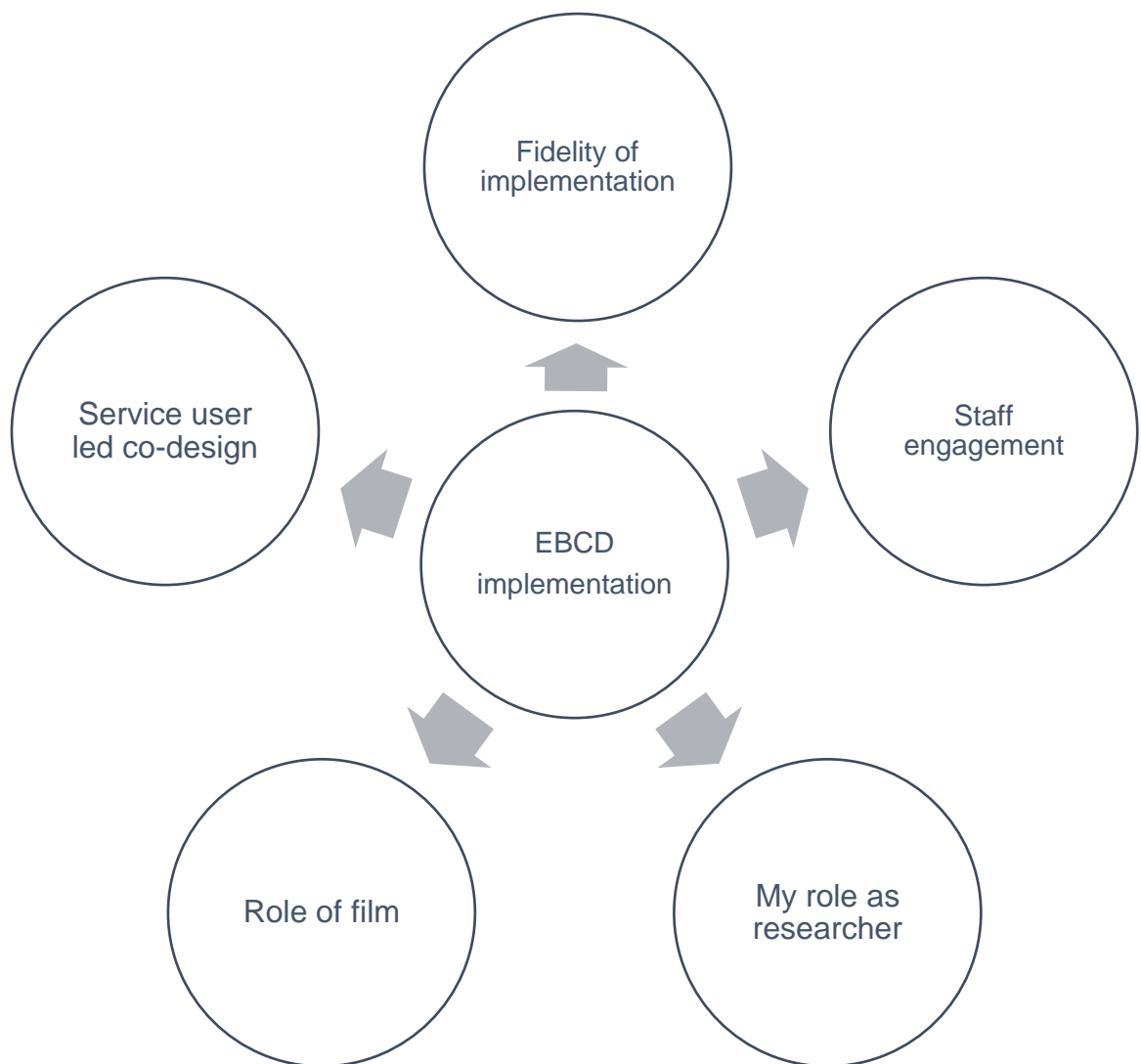


Figure 6-1 Findings

These factors were identified from Phase 2, 3, 4, and 5 (see Table 6-1) and are the key concepts underpinning the themes from these phases. Phase 2 & 4 identified that EBCD could be implemented as a QI intervention in a mental health setting and Phase 3 & 5 identified a range of themes, which were grouped under the concepts of fidelity of implementation, staff engagement, my role as researcher, the role of film and service user led co-design. These ideas form the basis for an explanatory model of how EBCD can be led by a service user group and successfully implemented in a mental health setting. These concepts will now be reviewed with reference to both the wider literature and the empirical findings from this study.

6.4.1. Fidelity of implementation in this study

The extent to which an EBCD QI intervention follows the EBCD model has implications for its successful implementation in any setting. The achievement of high

implementation fidelity is vital; it is the best way of replicating the success achieved through interventions developed by original research and secondly implementation fidelity contributes to the evidence base of the original intervention (Carroll et al, 2007). In Chapter 3, EBCD is described as a 6 stage process (Robert et al, 2015), these are;

1. Setting up the project
2. Gathering staff experiences through observation and in-depth interviews
3. Gathering patient and carer experiences through filmed narrative based interviews
4. Bringing staff, patients, and carers together to share their experience of a service and identify their shared priorities for improvement, prompted by an edited 30 minute 'trigger' film of patient narrative.
5. Small groups of patients and staff work on the identified priorities (typically 4-6) over three or four months.
6. Celebration and review event.

The literature about the use of EBCD as a QI intervention demonstrate that it can be powerful process for service improvement (Donetto et al, 2014). However using EBCD as a QI intervention does present challenges which highlight the importance of implementing EBCD with the right resources, (Larkin et al, 2015). Larkin et al (2015) also point to the definite distinctions between physical and mental health and that to use EBCD in a mental health setting, adaptations would be required to make it safe and effective (Springham and Robert, 2015). The EBCD intervention that was the focus of this study was undertaken by a service user group called Research Net, who led on all aspects of the EBCD process.

1. Setting up the project

For Bate and Robert (2007) this first stage of the EBCD QI intervention, involves establishing governance and project management arrangements and that this also ensures that senior clinical staff and senior managers are approached and are on board with the process, the King's Fund (2011) highlights this as a key enabler to the success of the project.

Research Net had a pre-existing weekly meeting that was utilised to assist with the setting up of the project, Research Net used this meeting to oversee the project and to plan how the project was to be implemented. Findings from the ethnographic observations of these meetings showed that the Research Net group discussed the ward to be selected for the implementation of EBCD, which senior clinicians and managers to approach and very much used these meetings to plan and oversee the project. In this regard, Research Net were mirroring the first stage of the EBCD process. However there was a slight difference, in that the researcher was also present

at the meetings on a monthly basis, and as the researcher had been involved in a previous EBCD project, Research Net used this as an opportunity to seek advice and support and clarify issues from the author's previous experience, this will be discussed in further detail later on in this chapter in section 6.6.5. The reason for the researcher's presence was to observe the EBCD project in its entirety, however the researcher's presence had a positive impact on the project in that members of the Research Net group sought advice and clarification and the researcher was able to offer support.

2. Gathering staff experiences through observation and in-depth interviews

The second stage of the EBCD process has two strands, non-participant observation of the work environment and interviews with staff, followed by an event at which the results of the observations and interviews are presented to the staff, (Bate & Robert, 2007). For Bate and Robert (2007) the observation allows an understanding of how and why things work and allows observation of how staff and service users go about their activities. Research findings have stressed that these observation and interviews provide useful insights into the staff patient experience and are a crucial component of EBCD, as they provide a hook for engaging staff in EBCD, (Donetto et al, 2014). The purpose of the interviews is to gather evidence as to how staff feel about their work environment, (Bate and Robert, 2007). Within this research the members of Research Net undertook the observations and staff interviews and also led on the staff event to present the anonymised results of the observations and interviews.

Findings from the interview data indicated that Research Net were actively involved in the observations of the ward and the interviews of staff members, there were a range of reactions from Research Net in undertaking these activities and these will be further explored later in this chapter, in section 6.4.2. Findings from the observational data from the staff event, demonstrated that the data from the observations and interviews was feedback to staff, the staffs' reaction to this was varied and this will be further explored later in this chapter, in section 6.4.3. Findings from this study showed that this second stage in the EBCD process was followed, however with a significant deviation, in that Research Net undertook the observations and interviews, this deviation will be discussed later in section 6.4.2.

3. Gathering patient and carer experience through filmed narrative based interviews

The next stage for Bate and Robert (2007) is the obtaining of service user and carer experience. Like the gathering of staff experience this has two strands: it is initially via the filming of patient experiences and then through a feedback event for service users to gather their perspective on their emotional touchpoints. The service user event is

another part of the development phase of EBCD identified by Bate & Robert (2007); it allows time and space for patients to talk about their personal experience of the service (Bate & Robert, 2007). Findings from this study showed that Research Net did not hold a service user event which is a major deviation from the EBCD process. Instead they recruited service users from amongst Research Net members themselves. Interview data from this study said that this was done deliberately, due to the impact of filming on mental health patients; this will be discussed in more detail later on in this chapter in section 6.4.4. This may have impacted on the EBCD project in that did Research Net obtain a broad enough range of patient experience, literature highlights that the EBCD approach does not obtain the views of all service users and that harder to reach service user views may not be heard, (Tsianakas, 2012). Limiting the service user experience to members of Research Net narrows the range even more.

The other strand to the gathering of service user and care experiences is the filming of service user experiences. This is highlighted by Bate and Robert (2007) as one of the most important aspects of the EBCD process; other literature also agrees with this (Donetto et al, 2014). In this research, findings from the observations and the interviews showed that films of service user experience were made although this was mainly from amongst the members of Research Net. This highlights two potential issues that may or may not have impacted on the outcome of the EBCD project under study; the combined use of Research Net as the implementers of the EBCD process and also of the patient experiences and, secondly, that there was filming from among the Research Net peer group, in that they were the people filming and being filmed. Potentially undertaking the filming in this way could lead to an element of bias in what was in the films, Research Net may have identified something through observations or interviews that they wished to highlight through the films and then emphasised this through the filming and editing process, or alternatively they may have missed something that was important to service users not able to contribute to the filming process.

4. Bringing staff, patients, and carers together to share their experience of a service and identify their shared priorities for improvement, prompted by an edited 30 minute 'trigger' film of patient narrative

The bringing of staff and patients together or the 'joint event' is the fourth stage in the EBCD process (Bate and Robert, 2007). It is usually the first time that staff and service users are brought together to share their experiences of giving and receiving care; it is also when the film of service user experiences is shown. Following the showing of the film, the event reflects on the touch points and selects what they wish to work on and identifies teams to work on the issues. The observational findings from this study

showed that the 'joint event' happened exactly as outlined in the EBCD process; staff and service users were brought together, the film was shown, a work stream was identified to work on the admission process and dates were set for the work streams to meet were made. There was no deviation from the traditional EBCD process, as outlined by Bate and Robert (2007).

5. Small groups of patients and staff work on the identified priorities (typically 4-6) over three or four months

The co-design groups of staff and service users work on the issue selected in the 'joint event' to improve the service. The groups should be a mix of staff and service users to continue the co-design element of EBCD, (Bate and Robert, 2007). This co-design part of EBCD is highlighted in the literature as being the very core of EBCD (Donetto et al, 2014). Findings from interviews in this study identify that the work streams happened and were a mix of members of staff and members of Research Net, who together over 5 sessions worked on improving the admissions process for service users, particularly around the information that is given to them when they are admitted. As with step 4 of the EBCD process, there was no deviation in this study to the EBCD process outlined by Bate and Robert (2007).

6. Celebration and review event

The final stage in the EBCD process as outlined by Bate and Robert (2007) is the celebration and review event, where the co-design groups come together to reflect on what they had done, celebrate success and plan for the next stage. The findings from this study indicate that this did not happen. The reason for this was that the Research Net group involved in the project moved on to other QI projects with the Trust. This could potentially lead to a change in the outcome of the project as it could lead to any improvements that were made being diminished; other literature suggests that when the co-design team were no longer actively involved, the benefits realised were reversed (Springham and Robert, 2015).

6.4.2. The radical nature of service-user led co-design

As has been highlighted there is no literature that demonstrates a service user group like Research Net leading an EBCD QI intervention. Previous literature has highlighted the benefits of using a service user group to film service user experiences (Springham and Robert, 2015). Others go further than this and argue that service users should take a much more direct role in improving healthcare services and be involved in identifying, implementing and evaluating quality improvement in healthcare (Robert et al, 2015). Findings from this study examine the evidence for a service user led EBCD project and

discuss the implications for this radical change to the traditional EBCD process (in contrast to previous projects which have been led by researchers or clinicians).

Service users leading a QI intervention such as EBCD would be a radical step in any healthcare setting but is particularly so in mental health. The power imbalance in healthcare between staff and services user is marked meaning that the service users' voice is seldom heard (Henderson, 2003). This is particularly so in mental health care, as not only are the service users a more vulnerable group than service users in a physical healthcare setting (Mulvale et al, 2016); the stigma that is associated with having a mental illness not only means that service users are not heard, but they themselves often do not speak up, (Dinos et al, 2004). Donetto et al (2015) highlight that in healthcare provision, there are clear demarcations between the provider and the recipient of care and that EBCD has the potential to blur these existing demarcations and discourses, as it introduces new discursive spaces that 'traverse people's sociocultural, professional and personal boundaries' (Iedema et al, 2010: p86).

The premise of EBCD is to bring staff and service users together to design services and it is precisely this bringing together of the two groups that begins to allow the possibility that the power imbalance can begin to be addressed, codesign for Iedema et al (2010), is about people coming together to negotiate the dynamics and developing new ways of engaging with each other. Previous literature describes EBCD as creating equal space for the staff and service users (Larkin et al, 2015) to work together on a common goal and it is this working together that allows the two potentially mistrusting groups to develop more positive intergroup attitudes and help readdress any power imbalance; this is consistent with other literature on contact with stigmatised groups which states that intergroup contact reduces intergroup prejudice, (Pettigrew and Tropp, 2006). The literature on EBCD says that involving service users from the very beginning of the EBCD process builds trust between all participants (Donetto et al, 2014). The benefits of EBCD to address the power imbalance between provider and recipient of care is that instead of the professional clinical expert applying their specialist knowledge to a problem, a social grouping involving all gathers to solve the issue based on their experience, (Iedema et al, 2015).

Findings from this study support the literature; observations from both the staff event and the joint event highlight that staff and service users were working together collaboratively and it appeared that barriers were breaking down between staff and service users. However, the interview data presented different findings between staff and service users, with service users and the facilitator feeling more positive about the breaking down of barriers and the facilitator feeling that a trusting relationship had

begun to develop between staff and Research Net. Whilst some staff agreed with this it was not the case for all the staff; further discussion of this difference in staff's response will be later in this chapter.

In contrast to the existing literature, within this study it was evident from the observations and interviews that Research Net as a service user group leading the EBCD project meant that the co-design aspect of EBCD occurred earlier in the EBCD process. With Research Net undertaking the interviews and observation on the ward and then being involved in the staff event, it felt to the researcher that co-design had started at the beginning of the project rather than at the joint staff and service user event. Interview data supported the researcher's observations with interviewees highlighted that the involvement of Research Net from the very beginning of the project, felt like the focus on improving the service was on how the ward was experienced by service users rather than how clinicians would deliver the service. One interviewee, the facilitator, who had been involved in previous EBCD projects felt the benefit of Research Net leading the project, was that they brought in a different, non-clinical mental health, skill set, which enhanced what the project focused on.

There was however, some issues with having Research Net leading the project, both with members of Research Net themselves and the members of staff (the staff response will be explored in the next section). Interview data from members of Research Net indicated that that they were very anxious about leading the EBCD project; for some it was an anxiety about the technical aspects of the process (were their interview techniques correct?), whilst for others it was more the emotional response to going back onto a psychiatric ward, as returning to the ward they had been on, brought back many bad memories for them. Indeed, one member of Research Net decided that the impact of these memories was such that they did not want to return to the ward. However, this was not the same for all members of Research Net who generally described leading the EBCD project as a very positive experience; it not only improved their confidence but also proved to be a cathartic experience for them. Interview data from Research Net indicated that it was the unity with the other members of Research Net that individuals found supportive and helped overcome their anxieties, which is supported by the literature (Springham and Robert, 2015)

The literature highlighted that major adaptations for running an EBCD project in a mental health setting is that mental health service users required support to be involved in an EBCD project (Cooper et al, 2015; Larkin et al, 2015 and Springham and Robert, 2015). Service users required support to prepare for the project and throughout the project due to the vulnerable nature of service users and the complex nature of mental

health services themselves, (Larkin et al, 2015). This was supported in the findings of this study, with interview data indicating the support that Research Net required in leading an EBCD project, from both the facilitator and the researcher, who had both undertaken previous EBCD projects; discussion on the support provided by myself as the researcher will be explored later in this chapter in section 6.6.5.

An issue that had been highlighted in the literature regarding the implementation of an EBCD project is the length of time the project actually took with some literature pointing to participants feeling the EBCD project was not cost effective in terms of time (Bowen et al, 2013); other literature stated that due to time constraints the full EBCD stages were not implemented, (Cooper et al, 2015) whilst other findings pointed to the fact the length of time an EBCD project took was an actual barrier to implementing EBCD in the first place (Donetto et al, 2014). The findings from this study support this with interview data from both staff and members of Research stressing the amount of time the project had taken and that this was viewed negatively, with some interview data highlighting a concern that with Research Net leading the project they did not have the skill set or more importantly the authority or power to get the project moving when obstacles arose. The findings from this research adds to this evidence base; the facilitator, in their interview, reflected on the length of time this project and others they had been involved in had taken. They felt that a definite project management skill set was required to successfully implement an EBCD project in all healthcare areas but particularly in a mental health setting, where the nature of clinical care is not generally time specific, although this needs to be carefully considered, as staff in this study, raised a concern that the project could feel to be 'compare led'. Previous literature has highlighted the amount of time an EBCD project takes but also has explored using an 'accelerated' EBCD process, where the traditional EBCD process is followed, with the exception that instead of locally made films, a national archive of pre-existing patient experience narratives was used, saving the time it took to make the films (Locock et al, 2014). This is something that could be considered for a future EBCD project in a mental health setting although it may run the risk of staff viewing the service users as not their service user and therefore not highlighting issues that need addressing locally.

The literature stresses the importance of the films of service user experience in the EBCD process, (Donetto et al, 2014). However the literature surrounding the implementation of EBCD in a mental health setting highlights the support that service users require in having their experiences filmed (Cooper et al 2015; Larkin et al, 2015 and Springham and Robert, 2015). Literature points to the traumatic effect for mental health service users in seeing their stories on film and also the issue of service users' identity being revealed on film, which due to power imbalances and the stigma

associated with mental illness, can be equally traumatic for service users (Larkin et al, 2015). Springham and Robert (2015) had utilised a service user group to film, edit and be the subject of the films to mitigate the trauma highlighted in the literature; this the authors state provided the support the service users required. The interview data for this study supports this, indeed some members of Research Net were involved in Springham and Robert's (2015) study and understood the traumatic nature of service users' narratives being filmed and set up a specific support group for those service users being filmed; this study adds to this existing knowledge base, as the advantage of Research Net leading the EBCD process was that they were able to identify and mitigate any potential issues and resolve themselves which gave the project credibility in the eyes of other service users.

In terms of whether EBCD as a QI intervention improves outcomes for service users, previous literature is limited. Tsianakas et al, (2015) identified improvements in outcomes for carers in terms of improved confidence in coping and Springham and Robert (2015) reported a significant reduction in complaints on the psychiatric ward where their study was undertaken. This study adds to this evidence base in that service user experience as measured by the Ward Atmosphere Scale (Moos, 1996) identified an extremely statistical significant improvement in seven out of the 10 subscales and very statistical improvement in one other sub scale. The actual co-designed intervention, the leaflet, was not particularly radical, as it brought together information that was available to service users but just not in one place. The radical nature of this EBCD project was service users leading the project and being involved in all aspects of the EBCD process, meaning that they were able to build relationships between staff and service users as a result of the process that was really important for improving service users' experience. In essence, the leaflet was inconsequential in itself; what mattered was the different type of staff/service user interactions.

6.4.3. Staff engagement

As was mentioned earlier in this chapter the findings from this study indicate that staff and the members of Research Net seemed to have different responses to the EBCD process. This seeming disparity in responses is supported by the literature which highlights that the different stakeholders involved in an EBCD process attribute different meanings to the process (Bowen et al, 2013 and Vennik et al, 2015). This difference seemed to affect the approach of the different stakeholders to an EBCD intervention, with the staff on the ground floor of the healthcare area that was in receipt of the EBCD intervention sometimes reluctant to be involved in the project. Vennik et al (2015) in their study highlighted that this was for fear of being criticised by service

users. The findings from this study's interviews with members of staff support this with interviewees saying they felt they were going to be criticised by service users; observational data showed that the members of staff appeared to be reluctant to be engaged in the project.

Literature also identified that frontline staff in a healthcare area often felt 'chosen' for an EBCD project by senior managers in their organisation, (Bowen et al, 2013); this contrasted with the service users who volunteered to be involved. Interview data from this study supports this and adds to the knowledge base with staff feeling their ward had been picked for the project by senior managers as part of some kind of 'investigation' into them or their ward. This feeling of being of being made to participate could potentially explain why the members of staff appeared - in the observational findings of this study - to be reluctant to be involved in the project. Interview data from this study highlighted that staff felt they were going to be criticised and that they found the EBCD process uncomfortable and unsettling, with members of staff concerned that they would 'say the right thing'; these findings support and add to the evidence base of Cooper et al (2015) who identified that staff in their study found the process intimidating. The interview evidence from this study identified that staff were concerned about working alongside service users that they had nursed when the service users were unwell and that - with Research Net being involved in the interviews and observations - there was a concern about issues of confidentiality. The interview findings from this study identified that staff also had anxieties about being involved in an EBCD intervention not just with regard to the process of EBCD (and issues around confidentiality with Research Net leading the project) but also feeling they were going to be criticised.

Observational and interview data from this study indicated that there was a difference in the staff and Research Net awareness of EBCD and what the purpose of it was, and why they were undertaking the project. This is perhaps understandable as Research Net - as the leads for the EBCD project - should have a greater understanding of the approach. However, it may be important to prepare the staff more for the project to ensure a successful implementation; findings from literature show that sceptical staff soon drop out of the process, thinking 'nothing will change' (Bowen et al, 2013). Such sentiments were supported by this study with interview data highlighting staff scepticism of EBCD as a QI process. An interesting reflection from the interview data from this study was a member of staff feeling that staff who had a greater affinity for patient experience were more aware of EBCD and more accepting of it as a QI process. Does this mean that EBCD cannot reach those difficult to reach, 'stuck in their way' staff who are precisely the ones a QI intervention like EBCD should try to reach.

Interview data from this study suggests that whilst initially it seemed that staff were sceptical that EBCD would make any improvements to care, this began to change over the course of the project and they became more hopeful of positive change.

A finding from the interview data for this study - not found in any of the previous literature - was the recognition of the power imbalance between nurses and patients (Henderson, 2003). Findings from this study indicate that nursing staff began to feel that through the EBCD process the power had swung too far to the service users; despite the members of Research Net being overwhelmingly positive about the positive impact that EBCD would bring, staff expressed concern that it was too service user focused and more consideration should be given to the staff (for example, staff saying that the 'rules have to work for us that are here all the time and know all the pressures').

Another finding from this study that has not been found in previous literature was that the interview data from some members of staff indicated that the benefit of having a service user group, like Research Net with service users that had previously been on the ward, meant staff got to see service users as people with a problem rather than problem service users. Interview data from staff in this study also point to some concerns about the project being led by Research Net, some staff felt that the service users involved in the project would not view the ward with an unbiased eye and that the service users may come into the project with their own agenda; other members of staff felt that at some points during the process, it was less co-design and more 'compere led' by Research Net.

Previous literature (Cooper et al, 2015) has highlight that EBCD projects do emphasis the role of service users and that more could be done to support the staff to increase their awareness of EBCD and its benefits. This could increase staff confidence to be actively involved in an EBCD project ultimately improving the co-design aspect of EBCD. The findings of this study support this and the researcher would strongly support future EBCD projects focusing a lot of time on supporting staff through the project. Indeed it is possible that with the staff feeling they had lost power to their senior managers and to service users that they actually require more time and support than the service users.

In terms of whether EBCD as a QI intervention improves outcomes for staff of the unit this is this first study to consider this. The Ward Atmosphere Scale (WAS) (Moos, 1996) undertaken pre and post the EBCD intervention, whilst indicating that there were improvements in nine out of the ten sub scales, none were statistically significant

(indeed one of the subscales, personal problem orientation, had actually got worse). So it appears that the improvements felt by service users following the EBCD intervention were not experienced by the staff on the same ward.

6.4.4. Role of film and visualising patient experiences

Previous literature has indicated the crucial role that the films of service users' narratives about their experience of receiving care play in the co-design process; the films act as a catalyst for this process (Donetto et al, 2014). The findings from this study support this and responses from staff suggest that the films played an important role for them on several levels; it started to break down the concept of the 'them and us' view in health care between staff and service users as the staff saw service users mentally well, discussing their experiences on film, thus allowing the staff to see the service users not just as service users but as people.

There was some concern that the films may increase the power imbalance between staff and service users if there was too much focus on criticisms or that staff would be only able to see the negative aspects of service users' narratives, become defensive and not be able to see beyond this. However, this did not happen and the films also highlighted positive aspects of service users' experience which the staff welcomed. The staff also felt the medium of film really helped them to see and understand where the issues on the ward were and they could see exactly how the issues affected service users, more so than simply being told what the issues were. This supports the literature regarding the impact that service users' filmed narratives have on an EBCD project as a catalyst for change (Donetto et al, 2014). Adams et al (2015) also highlight how films of service users' experience act as a 'trigger' for the involvement of staff and service users' involvement in the QI project. Adams et al (2015) draw on Gabriel's (2004) theory of "narrative contract", exploring how professionals' response to service users' narratives can change over time as to whether the narrative is seen as reliable and valid; nonetheless this study supports that at the initial stage that the filmed narrative was accepted as reliable and started the staff on a QI process.

Despite the recognition of the important role that film plays in the EBCD process, there has been caution raised in the literature surrounding the implementation of EBCD in a mental health setting. Of particular concern has been the level of support for service users when having their stories filmed and subsequently shown at the joint event due to the nature of stigma in mental health. In other projects when service users' anonymity was removed when they were filmed they needed a great deal of support through this part of the EBCD process, (Cooper et al, 2010; Larkin et al, 2015 and

Springham and Robert, 2015). The findings from this study, both support this and develop it further: interview data highlighted the traumatising affect that seeing their story on film has on mental health service users, so much so that Research Net set up a specific support group for people who are or have been filmed. Indeed, during this study, Research Net developed this concept even further and they felt that it was safer if it were members of Research Net who were filmed as they had their own support systems already in place.

Interview data from this study found that the making, editing and being in the films had a positive effect on the service user members of Research Net. Although they initially described anxiety about both being filmed and the process of making the films, in later interviews following the joint event when the films were shown, they described what a positive experience it had been and how proud they had been of the films they had made. This study's findings support the literature in the importance of service users' filmed narratives to an EBCD project but also add to the literature in the benefits this brings to a service user group like Research Net, if they oversee all aspects of the filming.

6.4.5. Reflections on my role as researcher

Literature has raised the importance of increasing training and support to practitioners to promote and develop the EBCD approach and also to support them in implementing an EBCD QI process (Donetto et al, 2014). Bowen et al (2013) highlight the need for specialists to help support an EBCD project to get it up and running; in an earlier study, Bowen et al (2011) discuss the importance of design researchers acting as facilitators to successfully implement an EBCD project.

In this study, as was highlighted in Chapter 4, section 4.3, I as the researcher had previously been involved in an EBCD intervention. I had worked collaboratively with an art therapist to implement EBCD on a different ward in the same NHS Trust in which this current evaluation of the EBCD process was carried out. In this previous project I was involved in all aspects of the EBCD process, from the observation of the ward, the interviews with staff, the patient event and the subsequent filming of the patients' stories. I also jointly facilitated the staff event and the joint staff and patient event with the art therapist and was involved in the setting up of the joint patient and staff work streams to co-design specific aspects of care. Using this previous knowledge, I was able to support the Research Net group in the build up to the EBCD intervention and during it, which is in essence the support that Donetto et al (2014) highlights is crucial

to a successful EBCD intervention. I was able to share my previous experience and knowledge to help them lead the project.

The sharing of knowledge is a critical issue across society, no more so than in health care, as a method of enabling innovation; it is a way for knowledge embedded within one community or organisational group to become available or known to members in a different community, (Wenger, 1998). The gap between knowledge held within healthcare research communities and healthcare providers causes a substantial delay between generating the research knowledge and the time this knowledge is used in practice (Lomas 2000)

A 'knowledge broker' is a term that has been specifically used in the context of the role that is played to transfer knowledge between different communities, such as research communities and health care providers; it has been suggested that while the number of relations across communities increases access to relevant 'external' knowledge, "a centralized position within an overall pattern of relationships determines whether such knowledge can be used beneficially" (Van Wijk et al 2008: 834). This centralized position is occupied by actors that effectively act as 'knowledge brokers', enabling the exchange of relevant knowledge within the social network (Burt 1992). However, the success of knowledge brokering depends on a series of factors that go beyond 'positioning'. The closeness of relationship between different organisational actors in the different communities, as reflected in 'tie strength' (Hansen 1999) and the building of trust between the different communities are decisive in effective knowledge transfer.

There were strengths and weaknesses in my role as the researcher being the 'knowledge broker', as I was in this study. As highlighted by Hansen (1999), a closeness developed between myself and the Research Net group and built up their trust with me as a researcher. At times it felt to me as the researcher that Research Net had regarded me as one of them, rather than a member of staff, which may not have happened as I am a trained psychiatric nurse. This trust meant that Research Net were more candid with me in their interview responses and they seemed not to be anxious in speaking to me, which is particularly important with mental health service users who often take time to trust people and open up to them.

As Van Wijk et al (2008) state, a knowledge broker is able to impart knowledge that can be used beneficially. In this study, I was able to share with Research Net my experiences of implementing an EBCD project, what went well and what went less well. I felt that this information increased the chances of the success of the intervention;

Research Net were aware of the possible pitfalls and were able to make allowances for them.

Despite these advantages to my role as a 'knowledge broker' to Research Net, there were some potential weaknesses. There was I felt a potential for myself as the researcher to become biased towards the intervention I was studying, rather than merely observing and reporting on the process. I felt at times that I wanted to intervene with some parts of the process, to try to speed up the process or make it more effective. There were also moments when I felt some form of responsibility towards the success of the EBCD project, rather than researching it; this was a less positive aspect of the knowledge broker role.

6.5. Original contribution to knowledge

The narrative review of literature in Chapter 2 suggested that EBCD could be implemented in a mental health setting but that specific adaptations would be required to implement EBCD in this setting. Only one study demonstrated that EBCD as a QI intervention improved outcomes, although none of the EBCD projects had been led by a service user group like Research Net. This study provides that evidence and also verifies that EBCD can be implemented in a mental health setting.

This study highlights the adaptations that are required to successfully implement EBCD in a mental health setting and confirms that being involved in an EBCD project has different meanings to different stakeholders in the process. The recommendations from this study is that a mental health service user group is best placed to film and be filmed about their experiences of mental health services, as without adequate and appropriate support, the experience of 'telling their stories' can be incredibly traumatic for mental health service users.

This is the first study that has exclusively focused on a service user led EBCD QI intervention and therefore provides empirical insights into what has been a previously unexplored area of research. It is an important first step in our understanding of service user contribution to quality improvement and has several implications for practice. The study identified that being service user led the co-design aspect of EBCD, described as crucial by Donetto et al (2014), began earlier in the process than a traditional EBCD intervention. Being service user led also had added benefits to both staff and service users; the staff got to see service users well and there was more regard for the process, rather than it was led by a researcher or a manager and for the service users, leading an EBCD process had a profound effect on their confidence and self-esteem and for some it became a cathartic process.

This study is the first to use a multiple methods approach with use of validated instrument (WAS) to demonstrate the impact of EBCD on patient and staff experience on a psychiatric ward. The study used ethnographic observations and semi structured interviews to evaluate the implementation and experience of the implementation of an EBCD project in a mental health setting, as led by a service user group. The study made recommendations around the leadership and skill set required to implement a successful EBCD project. The WAS demonstrated that although EBCD had a significant impact on service users of their experience of the ward, this was negligible for staff.

The study also used an exploration of fidelity to a traditional EBCD model, which had not been done before. Donetto et al (2014) in their report of the EBCD projects that had been undertaken, highlight several key areas that were crucial for an EBCD project; non-participant observation of work environments and filming of service users' narratives and co-design being the key areas. This study sought to understand whether EBCD could be implemented in a mental health setting and used fidelity to the traditional EBCD process to evaluate this.

This study also differed from existing literature as it was undertaken in a very 'close to' observational nature of the service user led EBCD process; previous studies have been reports of EBCD interventions undertaken by the people that led the EBCD process. This gave the study a unique understanding of the research area and meant that the author was able to explore and examine in more detail areas that previous studies have highlighted as potential issues (for example how the staff found the process).

This study built on existing literature around the impact on staff. Existing literature had highlighted that staff required support and that the process had different meanings for the different stakeholders, but this study highlighted how challenging it was for staff. Staff felt throughout the EBCD process there was a power imbalance, that they were at the bottom of; initially they felt this was between them as a ward staff group and their senior managers, who they felt had picked their ward for the project but then they perceived that the EBCD process being led by service users meant that the power had shifted from them to service users. Staff also highlighted that they found the EBCD process uncomfortable and they had concerned about working alongside service users (particularly around the service users observing the working environment and the staff were anxious that confidentially issues may arise).

6.6. Strengths

A major strength of this study is the multiple methods design of the research. There are strengths and limitations in both qualitative and quantitative research, however the use of both in a multiple methodology research design enabled the research to benefit from both. Indeed, Pope and May, (2006) suggest that qualitative research can complement quantitative research in several ways; it can act as a preliminary inquiry prior to quantitative data collection and it can validate quantitative research.

Basing the study on a single research site, (the acute psychiatric inpatient ward) and the staff and service users who work on the ward or have been treated on the ward, permitted for an in-depth exploration of the implementation of EBCD on the ward. The findings from the ethnographic observation of the key events in an EBCD process indicated that the EBCD process maintained fidelity to the traditional EBCD process, with adaptations and that EBCD could be implemented in a mental health setting. The members of Research Net and the staffs of the ward perceptions of the EBCD process were explored in the subsequent qualitative interviews, which further explored the fidelity to the traditional model and its applicability to a mental health setting.

The interviews revealed, through the use of thematic analysis, what the experience of being part of an EBCD process was for both the staff and the members of Research Net, who were leading the project and that the process had different meanings to the different stakeholders. These different experiences were also explored through the use of the validated and reliable quantitative survey, the Ward Atmosphere Scale (WAS), which highlighted that not only did the different stakeholders have a different perception of the process, but that the different stakeholders also experienced different outcomes as result of the intervention. The staff indicated that they experienced no improvement in the working environment, whereas the service users indicated a significant improvement.

Without a multiple methods approach the reasons for the stark difference between staff and service users experience post the EBCD intervention would not have been so evident and the reasons for this difference may have been falsely assumed. This highlights the inadequacy of using a single approach when researching phenomena related to complex processes of QI in clinical practice.

There has often been reported a lack of transparency in the reporting of multiple methodology study within health care research (O’Cathain et al., 2010) and this is crucial to assess the quality of any study. Throughout all phases of the study due attention was paid to ensuring that all methods were conducted with rigour. This was

important to ensure and enhance the trustworthiness of the data and reduce any potential bias.

6.7. Limitations

Conducting the study in a single research site allowed for in-depth exploration as noted above but there were limitations to this approach. A single case study limits the applicability and transferability of the findings to other settings, especially as there are significant variations in the organisation and provision of mental health inpatient services and community mental health services across both the UK and the world. Despite this the study did cover a typically diverse ward population and findings did resonate with the wider literature across other regions and countries. This does not mean the findings are irrelevant, but consideration will need to be given when applying to other contexts. Having just the single site meant that there was no control ward but rather just a pre and post intervention ward for the WAS survey. Inevitably this means it is not possible to ascribe the improvement to service user experience specifically to the EBCD process on the ward. The multiple methods approach of this study could not yield causal relationships between the EBCD intervention and the outcome of the WAS survey given the single site design; it could not be certain that EBCD caused the improvement in patient experience on the ward as this might have been due to some other factor; the use of a control ward could have compensated for this to some degree.

The site for the EBCD intervention was selected by the director of the mental health services in the mental health trust that the intervention took place; this meant that staff working in the care area did not volunteer to be involved in the project. This does not mean that the findings are irrelevant, but that consideration needs to be given as to the link between this and the result of the staffs' answers to the WAS survey. Staff in their interview responses highlighted that they were not sure why their ward had been picked for the project and were concerned as to the motives for the selection; this could have impacted on the way that they answered their part of the WAS survey and could account for the marked differences between service users' reports of their experience and staffs'. Consideration to this needs to be given when applying to other contexts and the use of a control ward may help to negate this impact.

Due to the single case study site design, there was also a degree of self-selection in the sample that occurred. It was not possible to interview everyone involved in the EBCD process; I only interviewed those who volunteered to be interviewed. Those who did volunteer to be interviewed may have had particularly strong views, positive or

negative about their experience, which may have skewed the data; their views may not have been representative of the wider staff and service user population.

From a personal perspective, the author had had considerable experience as a mental health nurse who had been involved in a previous EBCD project. Having worked as a mental health nurse on an acute psychiatric ward in the past and been involved in an EBCD project it was likely that my own preconceived ideas and assumptions impacted on the study. To manage the tension between being a researcher and nurse the author put a number of strategies in place to allow for a reflexive approach to the research process. These included keeping and reflecting on fieldwork notes, and explicitly considering this issue when collecting and analysing data. Additionally, a major role of supervision was to ensure that data was collected and analysed without undue influence from my personal views and this was helped by the fact that one of my supervisors was not a mental health nurse.

My role as the researcher also may have compromised the research process. As was mentioned in chapter 4, I came into this research as a person with previous knowledge of EBCD and spent time with Research Net prior to the intervention to help and support them with insights from my prior experience. This status as a 'knowledge broker', meant I had seen a successful EBCD project and that I was hopeful that this project would also succeed. My personal desire for Research Net to succeed and run a successful EBCD intervention could have impacted on the research process, as there was a danger that I stopped being a neutral observer and began to become involved, it was difficult to try not to intervene to sort out the problems, such as the lack of staff engagement or the issues with time delays. In order for this to be considered, when applying to other contexts it would be beneficial if a neutral person or group to the organisation undertakes the research.

Coming to the research as an 'insider' - or 'knowledge broker' - undoubtedly had its challenges but was also advantageous. I was able to identify this as an important issue to be researched and therefore expand and enhance the evidence base for EBCD as a QI methodology to bring about positive service user outcomes and experience in a mental health setting whilst providing rich insights into the underlying issues relating to the implementation of EBCD in such a setting. Finally, my interpretation of the data and suggestions for future recommendations are grounded in the reality of mental health care due to my knowledge and expertise of the field.

6.8. Implications for future practice

It is evident from the wider literature and this study that EBCD can be implemented in a mental health setting and that EBCD has an important part to play to improve the quality of care in an acute psychiatric ward and mental health care. This study has demonstrated that the perceptions and views of both staff and service users are that EBCD can be used in a mental health setting, but that certain adaptations are required for successful implementation and that the EBCD process has different meanings for staff and service users.

This study has highlighted that fidelity to the traditional EBCD model is key to successful implementation in mental health settings and other health care settings, it also allows for the process to be fully tested which can further add to the evidence base of EBCB as a QI intervention.

Service users leading the EBCD intervention has proved advantageous in a mental health setting for the success of the intervention, it has meant that the co-design aspect of EBCD, which Donetto et al (2014) had identified was crucial in the EBCD process, happened earlier in the process than with the traditional method. This is a key finding given that it is the staff and service users working together that is pivotal to QI in health care settings. In a mental health setting, this study has shown that service users leading the project has a positive impact for them; it became a cathartic process. Like the staff service users were initially anxious about the process (returning to a ward they had been detained and treated in) but as the process went on service users' confidence and self-esteem improved. Based on these findings I would suggest that in a mental health setting, given appropriate support, that a service user group like Research Net lead a similar project.

What this study has highlighted is that specifically within a mental health setting, due to the pace or lack of pace with which therapy occurs, that project management and leadership skills are required to ensure that the project stays on track and sticks to reasonable timescales. This could come from someone with previous awareness of undertaking an EBCD project, a 'knowledge broker', or it may be that within the service user group that there is someone with that skill set, but wherever the person comes from, service user, staff or research, it needs to be someone with a project management mind-set who is in charge of the project and 'owns' the project and ensures it meets the deadlines.

A clear recommendation from this study for further EBCD implementation in a mental health setting is that the filming of service users' narratives is undertaken by a service

user group (including the filming, editing and being filmed). Donetto et al (2014) highlighted the films as key to successful EBCD implementation and the literature that implemented EBCD also agreed with this. However, the literature (Springham and Robert, 2015), highlights that filming for mental health service users can be a deeply traumatic experience; this study supports this and goes further by suggesting that a service user group like Research Net are best placed to fulfil these roles, as they have their own support processes developed and any trauma can be addressed. Not only that but this study has shown that the making of the films had a positive effect on service users, who identified that being involved in the filming process improved their confidence and self-esteem.

A final recommendation from this study is that careful consideration needs to be given to the support that the staff receive prior and during the EBCD intervention, and that this potentially may be more support than service users require. The wider literature highlighted that staff felt they were going to be criticised (Vennik et al, 2015), that they were picked for the project by senior managers (Bowen et al, 2013) and that they found the process intimidating (Cooper et al, 2015); this study supports these earlier findings and identifies that is only by addressing this that staff will become more actively involved in the project.

6.9. Implications for further research

This is the first study that has attempted to explore a service user led EBCD intervention in a mental health setting and define the components of a successful implementation in that setting and explored perceptions from both staff and service users in the implementation. This has not been done in any other mental health care setting and replicating this study with other mental health services, for example community mental health services, would help to understand if the findings are generalizable and the issues common within mental health services.

This study was also conducted within a predominantly urban population and replicating the study within mental health services within a rural setting would help to understand if the findings are setting specific.

The use of the validated WAS was a useful tool for exploring whether EBCD made any difference to service user experience of receiving care on a psychiatric ward, however there was no control ward to rule out extraneous variables. Further research with a control ward should be undertaken.

6.10. Summary

- - multiple methods study design
- - fidelity of implementation
- - the radical nature of service-user led co-design
- - staff engagement
- - role of film and visualising patient experiences
- - reflections on my role as researcher
- - strengths and limitations

This chapter has presented the findings of the study and attempted to interpret these in the context of the narrative literature review. A model has been proposed for successful, service user led, EBCD implementation in a mental health setting based on the findings of the study. The strengths and limitations of the study have been highlighted, together with recommendations for both future practice and research. The final chapter of this thesis will provide some final conclusions on the future of EBCD in a mental health setting.

Chapter 7

Conclusions

As it has progressed this thesis has encompassed a wide range of issues and concepts each of which would deserve a study of their own: the impact of an EBCD project on the staff group; the therapeutic benefit of being involved in research on service users; the benefits of seeing a mental health service user as a person; the impact of service user led research on outcomes; how to engage staff in the co-design process; and many more.

Fundamentally, however, I believe this research has identified some very real issues relating to the implementation of a service user led EBCD QI intervention in a mental health setting in the contemporary NHS. Not only in terms of how to successfully implement EBCD in a mental health setting but also wider contextual factors such as how this process impacts on staff, how to do this within increasingly static or reducing resources whilst being required to meet national targets and demands given the increasing pressure on mental health services. The combination of these factors has the potential to make service user led QI EBCD interventions to be seen as not essential and therefore not seen as important by either managers or staff, without whom successful EBCD implementation would not be possible.

Critically rethinking how to put service users at the heart of the way mental health services are designed is key and is a major issue for the future. This has been recognised and acknowledged in the recently published Five Year Forward View for Mental Health (2016), which calls for greater emphasis to be put on people's experience to design and develop services, and highlights the importance of mental health service users as 'experts by experience' as being a key asset to this process. The strategy seeks to support much more research by experts by experience in relation to what matters most to mental health service users in terms of prevention, care and support with mental illness. The rationale being that there needs to be consideration of new ways to improve the quality of services and that 'experts by experience' are the most valuable asset to do this. This will entail a major shift in practice in mental health services, as services have previously been designed around the clinician but does offer the potential for service users to play a greater part in how services are run to move beyond purely biomedical responses to mental illness and for mental health services to consider all aspects of service user centred care. To realise this opportunity, service

users will need strong leadership, training and support to build confidence, clarity of role and the facility to both speak freely and have their contribution heard, strategies that have identified within my study.

The findings from my study show that to successfully implement co-designed QI interventions, then mental health staff need perhaps more support than service users to embrace the process. It is difficult to move away from the traditional model of 'them and us' in a mental health setting, as mental health staff seldom see beyond a 'problematic patient', and (in this case study) felt that EBCD was imposed on them by senior managers who were casting a critical eye on the care they provided. Staff were also concerned and anxious about working alongside service users. This diminished the potential impact on the experience for staff following the EBCD intervention and the successful implementation of EBCD.

However, in keeping with the national strategy, I hope this research will help to focus attention on some important issues in EBCD as a QI intervention and service user led research in mental health services and provide a new narrative and fresh thinking regarding implementing co-design approaches in such settings, particularly with regard to the crucial importance of service user led research in outcomes for services and service users.

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Appendix 1

Search Strategies

Service User Led Research

Search Terms: Service User and/or led and/or research		
Data Base	No. of papers	Search Date
British Nursing Index (BNI) 2004 to search date	41	22/05/16
CINAHL in EBSCO Host Publication date 2004 to 2016	6	22/05/16
PsychINFO in Ovid SP 2004 to 2016	6	30/05/16
PsychARTICLES in Ovid SP ® 2004 to 2016	6	30/05/16
Web of Science 2004 to 2016	199	02/06/16
TOTAL	258	

Participatory Action Research

Search Terms: Participatory Action Research		
Data Base	No. of papers	Search Date
British Nursing Index (BNI) 2004 to search date	155	20/07/16
CINAHL in EBSCO Host Publication date 2004 to 2015	468	03/09/16
PsychINFO in Ovid SP 2004 to 2015	74	31/12/16
PsychARTICLES in Ovid SP ® 2004 to 2015	5830	31/12/16
Web of Science 2004 to 2015	696	30/12/16
TOTAL	7223	

EBCD in mental health setting

Search Terms: Experienced Based Co Design in mental health settings		
Data Base	No. of papers	Search Date
British Nursing Index (BNI) 2004 to 2016	6	July 2016
CINAHL in EBSCO Host Publication date 2004 to 2016	0	July 2016
PsychINFO in Ovid SP 2004 to 2016	3	July 2016
PsychARTICLES in Ovid SP ® 2004 to 2016	3	July 2016
Web of Science 2004 to 2016	5	July 2016
TOTAL	15	

EBCD in health setting

Search Terms: Experienced Based Co Design in health settings		
Data Base	No. of papers	Search Date
British Nursing Index (BNI) 2004 to 2016	53	July 2016
CINAHL in EBSCO Host Publication date 2004 to 2016	0	July 2016
PsychINFO in Ovid SP 2004 to 2016	2	July 2016
PsychARTICLES in Ovid SP ® 2004 to 2016	2	July 2016
Web of Science 2004 to 2016	31	July 2016
TOTAL	88	

Appendix 2

Participant Information Sheet - Staff

Improving patient experience project:

Mental Health Ward

Staff Information Sheet

You are being invited to take part in an educational student study that is being undertaken at XXXXX NHS Trust by a student at King's College London. Before you decide whether or not to take part, it is important for you to understand why this study is being carried out. Please take time to read the following information carefully. Please contact the study researcher, Angus Gartshore, if you would like to discuss anything further. His contact details are provided at the end of this information sheet.

What is the purpose of this study?

The project seeks to improve the experiences of both those providing and receiving care on a mental health ward. An intervention called Experienced Based Co Design (EBCD) is being used on a mental health ward to improve the experience of both those providing and receiving care. This project aims to provide a unique opportunity for approximately 6 patients, and staff to discuss their experience of working alongside each other in experience based co design, to improve experiences on XXXXX ward, XXXXX NHS Trust. The Experience Based Co Design project is taking place on XXXXX Ward, and is being run by a service user research group, called Research Net. This study is not part of Research Net, but is seeking to understand how patients and staff experience being involved in the Experience Based Co Design Project

Why have I been chosen?

In this project, we are focusing on staff who have participated in the experienced based co design project carried out on XXXXX Ward. As a member of staff, you are ideally placed to tell us about your experience of trying to improve experiences of care here for patients of this service.

Do I have to take part?

It is entirely up to you to decide whether or not to take part. Please take time to read this information sheet.

What will happen to me if I take part?

There are three stages in this study (see below).

1. An anonymous questionnaire survey called the Ward Atmosphere Scale (WAS) before and after the EBCD intervention about the experiences of being on a mental health ward.
2. The chief researcher will observe two stages of EBCD, the staff event and the joint event with staff
3. An interview after the staff event and after the joint event about your experience of the process.

Stage 1 will involve you being invited to complete anonymously Form R of the WAS survey both before and after the Experience Based Co Design project has happened on the ward. The WAS survey is designed to measure how staff experience giving the care on a mental health ward and how patients experience receiving the care. This survey is completed by both staff and patients.

Stage 2 involves the researcher observing the two key stages in the experience based co design process; the staff event and the joint patient and staff event. Both stages of the project will be observed by the researcher.

Stage 3 will involve you being invited to attend an interview with the researcher, for up to an hour to share and discuss your experience of the process of experienced based co design on XXXXX Ward. If you would like a friend or colleague to come with you to this meeting then that would be fine. At this interview you will be invited to share your own ideas about your experience of being involved in the experience based co design process to improve services for patients.

The researcher intends to ask people to participate in the interviews before they participate in the experience based co design intervention and after it has been completed, this so there is a greater understanding of peoples experience throughout the intervention.

The stage 3 meeting (interviews) will be audio-recorded and may be used to share information about the experiences of being a participant in experienced based co design on a mental health ward. All audio recordings will be destroyed 18 months after the completion of the project.

How much time will be taken from my work schedule?

To participate in the project, staff will need to commit to a minimum of two one hour interviews (stage 3) over approximately a six month period. The researcher will also observe to staff event and the joint staff and patient event. We are aware that this project will take up some of your important time and we are grateful for that. However, we hope that you understand the importance of your contribution to improving both staff and patient experiences in the future. Your managers have agreed to support your time on this project. Refreshments will be provided. We will try to give you as much notice as possible about the date and timings of these meetings.

What are the possible benefits of taking part?

We expect the findings of this study to improve mental health ward services for patients. Although this may not benefit you personally, information you give may help influence and shape services in the future.

What information will be held about me?

We will follow ethical and legal practice and all information about you will be handled in confidence. If you choose to take part in the interviews, details of your particular experience will not be identifiable unless you choose to share this information with the group. Responsible members of the Kings College London may be given access to data for audit of the study to ensure we are complying with regulations and good practice.

The researcher leading the study, Angus Gartshore a student at Kings College London, will be responsible for security and access to the data. The data collected for the study will be analysed to learn more about the needs of patients, their families and/or carers. At the end of the study the research data will be secured for five years in keeping with standard research practice. Any personal identifiers relating to individual patients will be held for less than three months after the end of this 18-month study.

Any comments you make (or part of them) whilst participating in the project may be used in different formats such as paper and/or electronic to share with others. This may include other patients, carers and health professionals both for the purposes of this research project and for educational or service improvement purposes in the future.

What if there is a problem?

If there is a disclosure of bad practice or any safeguarding issues during the interviews then Angus Gartshore will raise this with the service director, Mr XXXXX, who will follow up on the concerns.

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. Please contact: Principle Investigator Professor Glen Robert glenn.robert@kcl.ac.uk

If you have a complaint, you should talk to your research doctor who will do their best to answer your questions. If you remain unhappy, you may be able to make a formal complaint through the NHS complaints procedure. Details can be obtained through the Guy's and St Thomas' Patient Advisory Liaison Service (PALS) on 0207 1887188, address: PALS, KIC, Ground floor, north wing, St Thomas' Hospital, Westminster Bridge Road, London, SE1 7EH.

This trial is sponsored by King's College London. The sponsor will at all times maintain adequate insurance in relation to the study independently. King's College London, through its own professional indemnity (Clinical Trials) and no fault compensation and the Trust having a duty of care to patients via NHS indemnity cover, in respect of any claims arising as a result of clinical negligence by its employees, brought by or on behalf of a study patient.

What will happen if I don't want to carry on?

You are free to withdraw at any time without giving a reason. A decision to withdraw at any time or a decision not to take part will not affect your employment either now or in the future. Any information you have provided with consent would be retained and used in the study. No further data would be collected or any other research procedures carried out in relation to you.

What will happen to the results of the research study?

Through this project we hope to learn more about how patients and staff can work together to improve experiences; we are likely to continue to use this way of working with other groups of patients as part of service improvement work. The results may be published in a professional journal or presented at a conference. They will also be shared with staff working elsewhere to help improve services elsewhere in England. If you would like a copy of the findings we will be happy to send you these.

Who is organising the research?

This study is being conducted by a student of Kings College London who is also a member of NHS staff , who is being supervised by researchers from King's College London. It has the support of the nurses and doctors and senior managers at XXXXX NHS Trust.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and given a favourable opinion by the NRES Committee. NRES Committee East of England - Norfolk

REC Reference number: 14/EE/1084.

Thank you for taking the time to read this information sheet. If you need further information, Angus Gartshore can be contacted as follows:

Angus Gartshore, Study Researcher

Angus.gartshore@kmpt.nhs.uk

Adult Community Mental Health Services, Kent Tel: : 01622 714559

Appendix 3

Participant information sheet - patients

Improving patient experience project:

Mental health ward

Patient Information Sheet

You are being invited to take part in an educational student study that is being undertaken at XXXXX NHS Trust by King's College London (KCL). The study is being undertaken by Angus Gartshore as a KCL student. Before you decide whether or not to take part, it is important for you to understand why this study is being carried out. Please take time to read the following information carefully. Please contact the study researcher, Angus Gartshore, if you would like to discuss anything further. His contact details are provided at the end of this information sheet.

What is the purpose of this study?

The project aims to provide a unique opportunity for approximately 6 patients and staff to discuss their experience of working alongside each other in experience based co design, to improve experiences of XXXXX Ward, XXXXX NHS Trust. The Experience Based Co Design project is taking place on XXXXX Ward and is being run by a service user research group, called Research Net. This study is not part of Research Net, but is seeking to understand how patients and staff experience being involved in the Experience Based Co Design Project

Why have I been chosen?

In this project, we are focusing on patients who have participated in the experienced based co design project carried out on XXXXX Ward. As a patient, you are ideally placed to tell us about your experience of trying to improve experiences of care here for other users of this service.

Do I have to take part?

It is entirely up to you to decide whether or not to take part. Please take time to read this information sheet in order to make up your mind.

What will happen if I take part?

There are three stages in this study (see below).

1. An anonymous questionnaire survey called the Ward Atmosphere Scale (WAS) before and after the EBCD intervention about the experiences of being on a mental health ward.
2. The chief researcher will observe two stages of EBCD, the staff event and the joint event with staff
3. An interview after the staff event and after the joint event about your experience of the process.

Stage 1 will involve you being invited to complete anonymously Form R of the WAS survey both before and after the Experience Based Co Design project has happened on the ward. The WAS survey is designed to measure how patients experience receiving care on a mental health ward and how staff experience giving the care on the ward. This survey is completed by both staff and patients.

Stage 2 involves the researcher observing the two key stages in the experience based co design process; the staff event and the joint patient and staff event. Both stages of the project will be observed by the researcher.

Stage 3 will involve you being invited to attend an interview with the researcher, for up to an hour to share and discuss your experience of the process of experienced based co design on XXXXX Ward. If you would like a friend or carer to come with you to this meeting then that would be fine. At this interview you will be invited to share your own ideas about your experience of being involved in the experience based co design process to improve services for patients.

Stage 3 meetings (interviews) will be audio-recorded and may be used to share information about the experiences of being a participant in experienced based co design on a mental health ward with other patients, carers and health professionals. All audio recordings will be destroyed 18 months after the completion of the project.

The researcher intends to ask people to participate in the interviews before they participate in the experience based co design intervention and after it has been completed, this so there is a greater understanding of peoples experience throughout the intervention.

What are the possible disadvantages of taking part?

Participation in the project will mean you will need to think about your experiences of the experience based co design intervention on Millbrook ward. The questions are not intended to be upsetting, but may raise concerns for you. If you feel that outside of the meeting you would like to discuss these concerns please contact Angus Gartshore. If you experience any distress following the interviews please contact XXXXX from Research Net who has organised support for people going through the Experienced Based Co Design, this support will be provide by members of research net, over seen by a clinical psychologist. XXXXX's contact details are XXXXXXXXXX. Refreshments will be provided and your travelling expenses will be paid for each of these meetings. The researcher will try to give you as much notice as possible about the date and timings of these meetings.

What are the possible benefits of taking part?

We expect the findings of this study to improve services for patients. Although this may not benefit you personally, information you give may help influence and shape services in the future.

What information will be held about me?

We will follow ethical and legal practice and all information about you will be handled in confidence. If you choose to take part in the interviews or the focus groups with other patients, details of your particular experience will not be identifiable unless you choose to share this information with the group. Responsible members of the Kings College London may be given access to data for audit of the study to ensure we are complying with regulations and good practice.

The researcher leading the study, Angus Gartshore as a student at Kings College London, will be responsible for security and access to the data.

The data collected for the study will be analysed to learn more about the needs of patients, their families and/or carers. At the end of the study the research data will be secured for five years in keeping with standard research practice. Any personal identifiers relating to individual patients will be held for less than three months after the end of this 18-month study.

Any comments you make (or part of them) whilst participating in the project may be used in different formats such as paper and/or electronic to share with others. This may include other patients and health professionals both for the purposes of this research project and for educational or service improvement purposes in the future.

What if there is a problem?

If there is a disclosure of bad practice or any safeguarding issues during the interviews then Angus Gartshore will raise this with the service director, Mr XXXXX, who will follow up on the concerns.

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. Please contact: Principle Investigator: Professor Glen Robert glenn.robert@kcl.ac.uk

If you have a complaint, you should talk to your research doctor who will do their best to answer your questions. If you remain unhappy, you may be able to make a formal complaint through the NHS complaints procedure. Details can be obtained through the Guy's and St Thomas' Patient Advisory Liaison Service (PALS) on 0207 1887188, address: PALS, KIC, Ground floor, north wing, St Thomas' Hospital, Westminster Bridge Road, London, SE1 7EH.

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What will happen if I don't want to carry on?

You are free to withdraw at any time without giving a reason. A decision to withdraw at any time or a decision not to take part will not affect the

standard of care received by you now or in the future. Any information you have provided with consent would be retained and used in the study. No further data would be collected or any other research procedures carried out in relation to you.

What will happen to the results of the research study?

Through this project we hope to learn more about how patients and staff can work together to improve their experiences; we are likely to continue to use this way of working with other groups of patients as part of service improvement work. The results may be published in a professional journal or presented at a conference. They will also be shared with staff working elsewhere to help improve services elsewhere in England. If you would like a copy of the findings we will be happy to send you these.

Who is organising the research?

This study is being conducted by a student at Kings College London who is also a member of NHS staff, who is being supervised by researchers from King's College London. It has the support of the nurses and doctors and senior managers at XXXXX NHS Trust.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, well being and dignity. This study has been reviewed and given a favourable opinion by the NRES Committee. NRES Committee East of England - Norfolk

REC Reference number: 14/EE/1084..

Thank you for taking the time to read this information sheet. If you need further information, Angus Gartshore can be contacted as follows:

Angus Gartshore, Study Researcher

Angus.gartshore@kmpt.nhs.uk

Adult Community Mental Health Services, Kent Tel: : 01622 714559

Appendix 4

Ward Atmosphere Scale

For use by Angus Gartshore only. Received from Mind Garden, Inc. on October 20, 2014

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www.mindgarden.com

WARD ATMOSPHERE SCALE

Instructions Form R

There are 100 statements here. They are statements about treatment programs. Please decide which statements are true of your programme and which are false. Please be sure to answer every statement and to fill in your name and the other information requested.

Please provide the following Information:

Today's date: _____

Your name or ID: Age:

Name of program:

Gender (Please circle): Male Female

How long have you lived or worked in this program? Years.....Months.....Days.....

If you are a staff member, check here

and indicate your staff position/title: _____

Please decide which statements are **true** of your program and which are not.

True - Circle the **T** if you think the statement is **true** or **mostly true** of your program.

False - Circle the **F** if you think the statement is **false** or **mostly false** of your program.

Please be sure to answer every statement.

Form R	True	False
1. Patients put a lot of energy into what they do around here	T	F
2. Doctors have very little time to encourage patients	T	F
3. Patients tend to hide their feelings from one another	T	F
4. The staff act on patients' suggestions	T	F
5. New treatment approaches are often tried in this programme	T	F
6. Patients hardly ever discuss their sex life	T	F
7. Patients often gripe	T	F
8. Patients' activities are carefully planned .	T	F
9. Patients know when the doctors will be on the unit	T	F
10. The staff very rarely punish patients by restricting them	T	F
11. This is a lively program	T	F
12. The staff know what patients want	T	F
13. Patients say anything they want to the doctors	T	F
14. Very few patients have any responsibility here	T	F
15. There is relatively little emphasis on teaching patients solutions to practical problems	T	F
16. Patients tell each other about their personal problems	T	F
17. Patients often criticize or joke about the staff	T	F
18. This is a very well organized program	T	F
19. Doctors do not explain what treatment is about to patients	T	F
20. Patients may interrupt when a doctor is talking	T	F
21. The patients are proud of this program	T	F
22. Staff are interested in following up patients once they leave the programme	T	F
23. T It is hard to tell how patients are feeling here	T	F
24. Patients are expected to take leadership here	T	F
25. Patients are strongly encouraged to plan for the future	T	F
26. Personal problems are openly talked about	T	F
27. Patients in this program rarely argue	T	F
28. The staff make sure that the unit is always neat	T	F
29. If a patients medicine is changed, a nurse or doctor always explains why	T	F
30. Patients who break the rules are punished for it	T	F
31. There is very little group spirit in this program	T	F
32. Nurses have very little time to encourage patients	T	F
33. Patients are careful about what they say when staff are around	T	F

Form R (continued)		True	False
34.	Patients here are encouraged to be independent	T	F
35.	There is very little emphasis on what patients will be doing after they leave	T	F
36.	Patients are expected to share their personal problems with each other	T	F
37.	Staff sometimes argue openly with each other	T	F
38.	The unit sometimes gets very messy	T	F
39.	The patients clearly understand the program rules	T	F
40.	Patients who argue with other patients will get into trouble with the staff	T	F
41.	Very few patients ever volunteer around here	T	F
42.	Doctors spend more time with some patients than with others	T	F
43.	Patients freely set up their own activities here	T	F
44.	Patients can leave the unit whenever they want to	T	F
45.	There is very little emphasis on making plans for getting out of this program	T	F
46.	Patients talk very little about their past	T	F
47.	Patients sometimes play practical jokes on each other	T	F
48.	Most patients follow a regular schedule each day	T	F
49.	Patients never know when staff will ask to see them	T	F
50.	Staff do not order the patients around	T	F
51.	Patients are quite busy all of the time	T	F
52.	The healthier patients take care of the less health	T	F
53.	When patients disagree with each other, they keep it to themselves	T	F
54.	Patients can wear whatever they want	T	F
55.	This program emphasizes training for new kinds of jobs	T	F
56.	The staff rarely ask patients personal questions	T	F
57.	It's hard to get people to argue around here	T	F
58.	Many patients look messy	T	F
59.	In this program, everyone knows who is in charge	T	F
60.	Once a schedule is arranged for a patient, the patient must follow it	T	F
61.	This program has very few social activities	T	F
62.	Patients rarely help each other	T	F
63.	It's ok to act crazy around here	T	F
64.	There is no patient government in this program	T	F
65.	Most patients are more concerned with the past than with the future	T	F
66.	Staff are mainly interested in learning about patients' feelings	T	F

Form R (continued)		True	False
67.	Staff here never start arguments	T	F
68.	Things are sometimes very disorganized around here	T	F
69.	Patients who break the rules know what will happen to them	T	F
70.	Patients can call nursing staff by their first name	T	F
71.	Very few things around here ever get people excited	T	F
72.	The staff help new patients get acquainted around here	T	F
73.	Patients tend to hide their feelings from the staff	T	F
74.	Patients can leave the unit without saying where they are going	T	F
75.	Patients are encouraged to learn new ways of doing things	T	F
76.	The patients rarely talk with each other about their personal problems	T	F
77.	In this program staff think it is a healthy thing to argue	T	F
78.	The staff set an example for neatness and orderliness	T	F
79.	People are always changing their minds here	T	F
80.	Patients will be transferred from this unit if they do not obey the rules	T	F
81.	Discussions here are very interesting	T	F
82.	Staff sometimes do not show up for their appointments with patients	T	F
83.	Patients are strongly encouraged to show their feelings	T	F
84.	Staff rarely give in to patients' pressure	T	F
85.	Staff care more about how patients feel than their practical problems	T	F
86.	Staff strongly encourage patients to talk about their past	T	F
87.	Patients here rarely become angry	T	F
88.	Patients are rarely kept waiting when they have appointments with staff	T	F
89.	Members never know when they will be transferred from this program	T	F
90.	It is not safe for patients to discuss their personal problems around here	T	F
91.	Patients often do things together on weekends	T	F
92.	Staff go out of their way to help patients	T	F
93.	The program always stays just about the same	T	F
94.	The staff discourage criticism	T	F
95.	Patients must make specific plans before leaving the program	T	F
96.	It is hard to get a group together for card games or other activities	T	F
97.	A lot of patients just seem to be passing time here	T	F
98.	The day room is often messy	T	F
99.	Staff tell patients when they are getting better	T	F
100.	It is a good idea to let the doctors know that they are in charge	T	F

Stop here.

Appendix 5

Account of EBCD staff event

EBCD – Staff Event: XXXXX – 10/12/14 - 9am – 1pm

I was first to arrive, soon followed by the ward manager (PC) and two members of Research Net , then and HCA, rest of the staff except a medic were ready to start for the 09:30 start time.

Late start due to technical difficulties

18 members of staff attended:

- OT – 1
- Ward Manager – 1
- Staff Nurses – 8
- HCA's (Health Care Assistants) – 5
- Psychologist – 1
- Modern Matron – 1
- Dr's – 1

9 members of Researchnet attended

Description of room

Neutral room (beige/mushroom coloured walls), blue carpet, 3 windows, paintings on the wall, large room, but not too big for all the people.

A rectangular table at the front, with a screen for presentations, four round tables in the room with chairs around for audience, each table had a mix of research net people (2 on each) and staff.

Content	Reflection
09:40 Introduction to EBCD – XXXXX talking, standing	Attentive staff, looking at presenter
09:45 Introduction to the day from XXXXX, director of service, he was stood up	Attentive staff, all looking at XXXXX, no talking to each, probably because he is the boss
09:55 N standing and talking explaining EBCD process	A couple of nurses looking at each other, difficult to tell what it was about, no talking, most appeared interested.
10:00 N describing what has been done to get to this point, discussed the observations and interviews, N standing and talking	Still paying attention, no talking
10:10 N feedback observations, acknowledged staff were working hard, saw pts waiting around a lot, ID'd differences between permanent & agency staff (N standing and talking) Description of problems with paperwork	Some nods around the room Not talking to each other, no comments A couple of nurses attention wandering, staring out the window Lots of nods around room
10:15 N talking, reflecting what it must feel like to be a patient	All sitting in silence, most looking at N, some looking at the table in front of them, 2 staff whispering to each other (not sure if they are agreeing or not)
10:20 N asked staff for their thoughts about the observations and interviews	A nurse spoke first (table 2), agreed with the problem of the paperwork, lots of nods around the room
10:21 N had to encourage comments	An HCA (table 4) agreed that face to face time with pts suffers, because of all other demands "feet don't touch the ground". Good participation beginning, lots of nods and agreements around the room, feels like the process is starting. Another HCA (table 1), gave example of having to search 20 rooms for drugs and having to fill out forms for each of them "What is expected of nursing staff is impossible"
10:23 Psychologist describes situation on ward in regard to patient interaction with staff and pressures staff are under. Sitting down on table 1	All staff paying attention to him, impression is he is well thought of by staff
10:25 N reflected back comments to people & asked XXXXX (Director), he highlighted disconnect between wards & community teams	XXXX spoke sitting down, all paying attention to him Lots of staff nodding at his comments, seems agreement around the room with the discussions
10:30 OT speaking, highlighting problems between ward s and community teams (table 3)	Lots of staff nodding, more wanting to speak, lots of talking amongst themselves, agreeing with all that is being said, lots of converstaions about what was being discussed on table 4
Staff nurse table 1 highlighting problems	lots of nods and agreement around the room

Content	Reflection
10:35 HCA table 4, highlighted the expectation of pts that their home life will be sorted whilst they are on the ward, also highlighted need for activity worker on ward	HCA using this opportunity to ask for more resources on ward, generated a lot of conversation between staff on table 4 (all in agreement)
10:37 Nurse table 2, highlighted carer expectations and that the ward can sometimes feel like a dumping ground	Everyone paying attention to this nurse, lots of nods and 'ahmens' in agreement
10:42 Discussion led by N (standing up) and psychologist (sitting down) about the expectations of patients and carers, that patients will be cured on the wards and this is not the case	All listening to conversation, lots of nods from table 4, two people on table 3 taking notes, unsure about whether this was about the discussion or they were doddling
10:48 N asked Researchnet for comments	XXXX – Researchnet, said what really shocked them was how hard the staff worked; this was very well received by staff. NB/ this feels like the beginning of staff and patients working together, due to research net being a mix of patients & former patients
10:51 XXXXX (table 1) highlighted +ve feedback for staff	Some people looking at him, 1 nurse table 4 checking her phone, but some nods around the room
10:53 XXXXX Researchnet table 1, had also recently been a patient on Millbrook ward, highlighted the good practice she saw on the ward when she was a patient and reiterated how hard she felt the staff worked	Lots of agreement around the room, generated a lot of good discussion around the room and difficulties on the ward, with most people joining in. I think the staff really felt valued and appreciated by the patients from researchnet
10:59 a nurse raised a desire for psychology supervision for nursing staff	It feels like staff are acknowledging the difficulties they face on the ward and not just in a moaning way, but are actively looking to how they do it better
11:05 Discussion led by N about working with researchnet, centring around patients who are well	Lots of nods around the room, from all tables, it feels as if there is a complete understanding of the ethos of working with EBCD
11:10 Coffee Break	Good discussions over coffee around EBCD and the process of staff and patients working side by side, appears to be a consensus that it's a good this
11:20 Consultant Psychiatrist arrives	Seems unsure about what EBCD is all about, feels like he's not sure why he is here
11:40 back from coffee break	All return on time from break
11:41 N led discussion on a patient journey into the ward and the emotional touch points along that journey	People all paying attention to N. This feels different to the pilot on XXXX ward, when it felt hostile, I think it is because research as ex patients (4 had been on the ward) are involved right from the beginning conducting the interviews and observations

Content	Reflection
11:52 N, standing, facilitated discussion around process and touch points, talked about 'patient touch points'	Really good discussion from tables 1,2 & 4. Table 3 nodding, staff on table 2 highlighted patient touch points, good understanding of the process
11:55 Started focus groups on each table, Neil asked each table to think about what type of patients research net should interviewed and also highlighted the emotional touch points. All tables were a mix of research net and staff	Started by everyone introducing themselves, all seemed actively engaged in the process and in discussions, except the consultant psychiatrist who was looking at his phone for about 5 mins. All four tables actively engaged in discussing emotional touch points on the patient journey NB/ having researchnet here has, I feel started the EBCD process earlier than in the XXXX pilot
Table 1 2 researchnet Psychologist 2 HCA's 2 nurses	Great conversations, talking together, all on table involved, researchnet & staff
Table 2 2 researchnet (1 very quiet) Consultant Psychiatrist Ward Manager 1 nurse, 1 charge nurse 1 HCA	Less animated conversations Dr kept looking at his phone, HCA and 1 researchnet person very quiet, Perhaps because Dr & ward manager were on the table
Table 3 3 researchnet Modern Matron OT 2 nurses	Really good conversation between research net & staff
Table 4 2 reseach net 2 HCA's 2 nurses	Really good conversation between research net & staff
12:40 feedback	Table 4 had to be reminded to stop discussions, they were continuing to discuss EBCD and emotional touchpoints, showed good engagement with the process.
Table 4 Highlighted wanting an understanding of patient expectation and what was seen as good Suggested a sample of 1 st admissions and repeat admissions, both sectioned and informal	Good understanding of what they were supposed to be doing Feedback came from researchnet
Table 3 Understanding patients expectations of admissions and what could be done better Look at how restraints are carried out Suggested the same patient group as table 4	Good understanding of what they were supposed to be doing Feedback came from researchnet

Content	Reflection
<p>Table 1</p> <p>Good that a senior manager was here</p> <p>+ve feedback of ward</p> <p>Extra information for patients</p> <p>Usefulness of peer support workers</p> <p>Talked about experience of 'guesting' (staying on the ward but no actual bed)</p>	<p>Good understanding of what they were supposed to be doing</p> <p>Feedback came from researchnet</p>
<p>Table 2</p> <p>Expectation of patients of ward</p> <p>The part the patient played in their treatment</p> <p>1st impressions of the ward</p> <p>Ward rounds</p>	<p>Staff member of researchnet feedback</p> <p>Also good understanding of what they were supposed to be doing</p> <p>Comments from the Dr demonstrated that he didn't really understand the process of EBCD he was talking about a small sample size and not being relevant, N point out this wasn't a research study but a redesign process.</p> <p>NB/ he turned up half way through the morning and was on his phone</p>
<p>12:50 N summed up, standing up</p>	<p>Lots of nods and mummings of agreements about what EBCD is aiming to achieve, room felt positive and it felt hopeful for the outcome of the EBCD project on XXXXX ward</p>
<p>13:00 Lunch</p> <p>Everyone stayed for lunch</p> <p>Everyone sat and ate together, i.e. researchnet and staff all sitting together</p>	<p>Discussions around emotional touch points continued and how this process would be a great way to look at how services are delivered.</p> <p>Very positive feeling over lunch about the EBCD project on XXXXX and how EBCD could help with redesigning how the care is delivered on the ward.</p>

Appendix 6

Interview questions for ward manager

Interview questions for the ward manager

- How did EBCD come to be on your ward, how did that feel?
- What was your awareness of EBCD prior to this?
- What's it like having ex patients observing the ward and interviewing staff?
- What were your expectations and anxieties prior to the staff event?
- How did it feel actually on the staff event?
- How well engaged were the staff during the event?
- Any anxieties or reservations about what will happen after the event?
- Have there been any conversations about EBCD since the event?
- Have you picked up any concerns/ reservations from staff following the event?

Appendix 7

Interview schedule for the staff on the ward

Interview schedule for the staff on the ward

- What was your awareness of EBCD prior to the staff event?
- How did it feel to have ex patients observing the ward and interviewing staff?
- What were your reflections of the staff event?
- Any anxieties or concerns following the event?
- What is going to be happening next?
- Where do you think this will lead in the future?

Appendix 8

Interview Schedule for members of Research Net

- Did you do the interviews/observations of the ward?
- How did that feel?
- Were you a patient on the ward, if yes, how did that feel?
- What was your experience of being a patient, positive or negative?
- What were your expectations of the staff event?
- What were your anxieties before the staff event?
- What was your experience of the staff event?
- Was there anything that surprised you about the staff at the event?
- What are your expectations/anxieties for what happens next?

Appendix 9

Interview schedule with the facilitator

- What was your reflection of the staff event you facilitated?
- How did it compared to the EBCD intervention we had previously implemented?
- What are the benefits/issues with Research Net implementing EBCD?
- What are your reflections about successful implementation of EBCD in a mental health setting?
- What do you see as the next steps in this implementation of EBCD?

Appendix 10

Account of the joint EBCD event

Joint EBCD Event – XXXXX, 22/10/15

09:00 for 09:15 start – 13:00 then lunch

XXXX room; neutral smallish room, red carpet, no pictures on the walls, two windows, three tables, plus table at front for laptop, projector etc.

I arrived at 08:15, 2 people from Research Net were already there, 3 others from research net including both staff leads arrived soon after me, the NS (facilitator) arrived.

At 08:30 – 1 member of staff arrived

At 08:40 – 2 members of Research Net arrived

At 08:45 – 2 members of staff plus three members of Research Net arrived

At 08:48 – 3 members of staff arrived plus two members of Research Net arrived

At 08:55 – 2 members of staff plus 2 members of Research Net arrived

At 09:05 – 5 members of staff arrived

At 09:09 – 1 member of staff arrived

(two more members of staff were due, but would be late as they had prior commitments (1 childcare and one was seeing a patient (psychologist)).

Staff included – Occupational Therapist, Modern Matron, Ward Manager, Charge Nurses, Consultant Psychiatrist (same one as was at the Staff Event), Nurses, Health Care Assistants.

Staff – 16 people

Research Net – 12 service users plus two members of staff who support Research Net

No IT issues, laptop and projector and films were set up at 08:30 to ensure everything was working correctly.

I sat at the back of the room in the right hand corner.

Content	Reflection
09:00 All Research Net left room to prepare for morning	Staff left in room with N facilitator, whispered discussions going on, people getting tea & coffee, catching up with each other. The trust has clearly implemented a uniform policy (corporate polo shirts), some staff were wearing uniforms, others weren't, also some had trust ID badges on, a clear demarcation of them as staff.
09:10 Research Net returned to the room and separated themselves of to three tables	Research Net didn't all sit at the same table, they had a plan of who was to sit where.
09:14 I introduced myself as a researcher of the EBCD process and gave out info leaflets, said I would be taking notes at the back and asked if everyone was ok with that	I noticed that there were a lot of the same members of staff that had attended the staff event in December 2014.
09:15 Event started on time. N opened the day with some house keeping	Awkward start, Staff & Research Net had sat where they wanted.
09:16 XX Staff member for Research Net that spilt everyone up and designated who sat where	This mixed people up and seemed to break the ice and people began talking
09:20 N asked everyone on each of the three tables to introduced themselves to each other	This relaxed people more
09:22 N kicked off the event, reminded everyone that staff event has been on 11/12/14. He then recapped on what EBCD is actually about	All in room were paying attention, although it was of note that there was senior manager from the Trust in the room, there was at the staff event.
09:26 N articulated the difference with using EBCD as a quality improvement as it focuses on the design and developing prototypes/pilots	All paying attention
09:33 N discussing emotional touch points	Person on table 2 (staff member) making notes
09:35 N reminded room of ward observations from Research Net. Hardworking staff Patients Waiting Agency staff not fitting into ward culture Too ward round focused	Lots of nods from all three tables in recognition of what was being said
09:37 N asked for comments	1 st comment was from Dr (table 2), reflecting on what they (ward) had tried to do. Reply from Nurse (table 1) & Ward Manager (table 1). There then began lots of conversations between members of staff on the tables, seemed to be agreeing to what was being said and highlighted by NS

Content	Reflection
09:40 A member of Research Net on table 1 reflected on Issues on the ward	Again lots of conversations and nods from staff seemed to be in agreement with what was being said
09:41 N feedback patient experience of life on a ward. N then asked for comments	Nods of agreement from both staff & Research Net. HCA started (table 1) agreed with reflections, Research Net (table 3) agreed with reflections and added comments.
09:45 N described a process map of an admission to a ward and added emotional touchpoints.	People paying attention 2 staff on table 1 talking together, seemed to be about points being raised
09:47 N asked for comments	Dr (table 2) responded 1 st , agreeing with comments Research Net (table 1), responded also agreeing with comments. Seems to be good agreement on table 1 & 2 about the value of the process
09:52 N introduced the concept of the films, asked people to jot down the emotions and points that were raised during the films, said the films was split into four parts	Everyone grabbed pens and pads of paper that were on the table
09:53 Another member of staff arrived	Sat at table 3
09:55 1 st part of film started Tell us about your admission	Staff clearly noticed that members of Research net that were sitting on the tables with them were also in the films telling of their experiences of being on a psychiatric ward. Everyone making notes as directed by N
09:58 N asked tables to discuss and agree on 3 or 4 key touch points SCARY CONFUSION WAITING ISOLATION	All 3 tables participated in discussions, very open conversations. Research Net (pt members) on each table seemed initially nervous, but very quickly opened up and discussed how their admission felt to them. Nurses on table 1 reflecting that was how they felt when they 1 st went onto a ward as a student nurse. Table 1 had three conversations Table 2 had one conversation Table 3 had two conversations
10:01 N said 3 or 4 more mins	Tables began to sum up their discussions, 'it really feels as co design is already starting', doesn't feel like a, them and us. Staff on table 1 reflecting that they don't stop and think how it feels for patients. Staff seem to be beginning to empathise with patients.
10:05 N asked tables for feedback	Tables all carrying on their conversations
10:06 Table 1 feedback	Research net (pt) led, staff supported her. Not talking over her, but adding to her comments, lots of joint working

Content	Reflection
10:07 Table 2 feedback	Research net (pt) led, supported by another Research net (pt), little input from staff on this table, ? this is the table with the Dr on. Although on direct questioning from N, staff responded.
10:08 staff & pt research net from table 1 chipped in	Table 1 seems more co design than the other two tables, more participatory between staff and pt members of Research net
10:10 Table 3 feedback	Research net (pt) led, nods on table 3, conversations between staff members, seems agreement to what is said.
10:12 2 nd part of film started positive points	Everyone taking notes, paying attention, whole room seems actively involved in the process.
10:15 1 member of staff arrives (late) psychologist, sat on table 3	Seemed to be an understanding he would arrive late (no second looks at him)
10:16 N asked for table discussion NORMALITY TALKING SAFETY PERSONAL TOUCH <i>These points agreed as key touchpoints</i>	As it was about +ve experiences, it appeared to me that staff seemed reluctant to start talking. On all three table the members of research net had to start talking first and then staff responded, it seemed almost as if the staff are either reluctant to acknowledge their good points or they too modest.
10:17 Conversations on all three tables	Very interactive on all three tables
10:18 N says 2 more mins	No one seemed to pay him any attention, everyone on the tables seems able to put their point across, no one seems more dominant than any other on any table
10:20 N asked for feedback	All tables still talking
10:21 Table 1 feedback 1 st	A member of research net feedback, supported by another member of research net, an OT chipped in, no other member of staff commented
10:23 Table 3 feedback 2 nd	A member of research net feedback, rest of the table nodding in agreement, support from table 1
10:25 Table 1 feedback 3 rd	A member of research net feedback, nods from the rest of the table
10:26 N asks for feedback and discussion	Lots of conversations on all 3 tables, laughter and agreement, the room feels very positive, each table is very reflective on the points that have been brought up
10:29 3 rd part of film started Less positive experiences	All taking notes
10:35 A pt on the film mentions night staff are not very nice	Lots of conversations between staff on table 1

Content	Reflection
10:36 3 rd part of film ends COMMUNICATION NIGHT UNSAFE <i>These points agreed as key touchpoints</i>	N didn't need to ask for tables to begin discussions, lots of spontaneous conversations started on all three tables, initially about night staff, but then all aspects of the film segment. Dr on Table 2 more involved, now seems to understand EBCD more than he did at the staff event (NB, it was the same Dr at both events)
10:39 1 nurse (charge nurse) on her phone	Not paying attention, looking like she doesn't want to be there.
10:40 N said 2 more mins	This same nurse started joining in with the conversations
10:42 All tables still talking	N needed to prompt them for feedback
10:43 Table 3 feedback 1 st	A member of research net feedback, table 1 still talking
10:44 Table 1 feedback 2 nd	A member of research net feedback, supported ball all table, lots of comments, table 3 continuing to discuss issues (staff & pts)
10:45 discussion on table 1 continues	Table 3 discussion also continuing, lots of nods and agreement to what is being said on Table 1
10:47 Table 2 feedback 3 rd	A member of research net feedback, nods from the rest of table 2 but no other comments
10:50 Final segment of film is shown What could be improved?	All taking notes, lots of nods around the room about comments that were being made on film by patients
10:56 Final segment ends, all tables started discussions COMMUNICATION EVERYONE'S MORE DIFFICULT AT THE BEGINNING FACE TO FACE <i>These points agreed as key touchpoints</i>	Again N didn't need to ask them to start talking. Also it seemed that others who hadn't spoken as loudly, spoke 1 st on all three tables (both staff and patients)
11:01 N asks for feedback	All three tables still talking
11:02 Table 1 feedback	A member of research net feedback, lots of support and discussion around the whole room
11:05 Table 2 feedback	A member of research net feedback, people from other tables joining in with comments
11:07 Table 3 feedback	A member of research net feedback, lots of discussion around the room about what it means to treat each other as humans, the segment of the film highlighted the cleaner as being the nicest person on the ward. Good interactions here between staff and patients

Content	Reflection
11:10 Coffee Break	Good mixing between staff and patients in the break, good example, DR walking out of room deep in conversation with a patient about the film and the issues it was raising. All conversations seemed to be about the films, no one group was isolating itself, no cliques, staff and research net mixing freely
11:30 N called everyone back. Asked everyone to go back to their tables, and ID 3 key areas that they wanted to look at, but not to think of solutions	People paying attention, all back from break on time, all seemed keen to continue discussing film and issues. Good discussions on all three tables, everyone participating, no one disinterested, everyone paying attention to each other, not speaking over each other. Everyone seems to be having an equal voice, HCA seems to have the same input as the consultant as a member of research net. Lots of discussions and laughter on all three tables Even though there has been a 10 month gap between the staff event and this joint event, this joint event feels as if it is going very well, with lots of co working between staff and patients.
11:58 N asks the room to start concluding their discussions	All tables continue their discussions, no one talking over each other. NB feels as of staff patient “them & us” barrier has disappeared.
12:06 N calls them all back, asks for feedback	Lots of agreement on tables, lots of nods to each other
12:07 Table 1 Feedback ADMISSION ACTIVITIES ROUTINE	Member of research net feedback, (table 3 continuing with their discussion) rest of table 1 joining in discussion, adding comments
12:10 Table 2 Feedback COMMUNICATION ACTIVITIES PAPERWORK/PROCEDURES INITIAL CONTACT	Member of research net feedback, supported by staff on the table, Dr’s comment demonstrated that he understood principles of EBCD, much more so than he did at the staff event, understands the design process, “need to think how we free up time to be with patients”.
12:15 Table 3 Feedback ORIENTATION ACTIVITIES PERSONALISED CLINICAL CARE	Member of research net feedback supported by rest of the table Lots of joint agreement across the room and also lots of laughter across the room. There is not one person, staff or patient, who is not involved in the discussions, nobody secretly checking their phones
12:20 N asks whole room to think about identifying 1 or 2 workstreams	Lots of agreement across the room about the four key areas

Content	Reflection
12:28 N summarises the points made	<p>4 key areas</p> <p>Admissions</p> <p>Activities</p> <p>Routine</p> <p>Paperwork</p> <p>Whole room is in agreement with the 4 points.</p> <p>XX (ward manager) says they should focus on 1 workstream only, lots of agreement in room, people feels it will be likely that if they focus on 1 thing it will get completed</p>
12:30 N asks room to vote on which workstream they want to do	<p>Admissions - 22</p> <p>Activities - 2</p> <p>Routine - 3</p> <p>Paperwork – 0</p> <p>Room opted to go for the admission workstream, lots of conversations continued after the voting about why this is important, room very keen on focusing on the first hour, which is a patient's first impression of the ward, and the first of their admission. Dr wants to call this "The golden hour", lots of laughter about this.</p>
12:39 N reminds the room that this is now about being practical and trialling processes and prototypes	Whole paying attention, asking appropriate questions
12:42 Discussion continues	Conversations are continuing
12:43 N asks room to join the workstream, a working group of 6 to 7 people, equal numbers of staff and members of research net, to meet every couple of weeks, NS will support	Decision made as to who is in the group, XYZ from Research Net & XYZ from the ward. Date set for 20/11/15 for first meeting, Research net and XX (ward manager) to co-ordinate.
12:45 XX Staff member of research net thanked the room and thanked N for being the facilitator	Round of applause at end
12:50 Break for lunch	Whole room went to have lunch together, conversations continued over lunch, research net and staff were all mixed up, research net hung back to discuss morning, all felt event went really well, the feeling was that the staff are up for the challenge and work with research net to improve how patients experience an admission to the ward.
13:30 Event ended	

Appendix 11

Interview schedule with ward manager post the joint staff & patient event

- What were your expectations of the joint event?
- What were your anxieties before the joint event?
- What were your views of research net being involved in the project? Have these changed since the joint event?
- How was it working alongside patients you had nursed on the ward?
- What was your experience of the joint event?
- Was there anything that surprised you about the joint event or the films?
- What did you make of the films?
- What did you think of the 'golden hour' suggestion?
- What are your expectations/anxieties for what happens next?
- What do you think success will look like?

Appendix 12

Interview schedule for staff following the joint staff and patient event

- What were your expectations of the joint event?
- What were your anxieties before the joint event?
- What were your views of research net being involved in the project? Have these changed since the joint event?
- How was it working alongside patients you had nursed on the ward?
- What was your experience of the joint event?
- Was there anything that surprised you about the joint event or the films?
- What did you make of the films?
- What did you think of the 'golden hour' suggestion?
- What are your expectations/anxieties for what happens next?
- What do you think success will look like?

Appendix 13

Interview schedule for Research Net following the joint staff and patient event

- What were your expectations of the joint event?
- What were your anxieties before the joint event?
- What was your experience of the joint event?
- Was there anything that surprised you about the event and the films?
- What did you think of the 'golden hour' suggestion?
- What was your experience of making and showing the films?
- What did you think of the staff's response to the films?
- What are your expectations/anxieties for what happens next?
- What do you think success will look like?

Appendix 14

Interview schedule for facilitator following the joint staff and patient event

- What were expectations before the joint event?
- What were your anxieties before the joint event?
- What was your experience of the joint event?
- What are your expectations/anxieties for what happens next?
- What do you think success will look like?
- What do you think the benefits of using Research Net as the patient group is? Any problems?
- How many EBCD projects in Mental Health have you undertaken and how is this one in comparison to the other projects in the trust?
- Do you think it's the task or the working together that makes EBCD successful?
- Would you have done anything differently?
- What do you think makes for a successful EBCD project in a mental health setting and is this different to a physical health setting?

Appendix 15

Examples of Coding of field notes from observation of EBCD events

Code	Description
Attentive	This code relates to researcher's observations that staff were paying attention to what was going on at the event
Interested	This code is specifically used to describe the researcher's reflections that the staff are actually interested in what is being said or discussed
Agreement	This is a code that reflects that the staff are not only interested in what is being said but are in agreement with what is being said
Overworked	This code highlights what staff said about their workload on a day to day basis
Stressful	This code relates to the negative feeling from staff highlighting the work issues they face day to day
Highlighting nursing issues	This code is specific to the description from staff about the nursing tasks they need to carry out with patients
Staff on board	This code is specifically used to describe the researcher's reflections that the staff appear to have embraced the EBCD concept
Taking notes	This code is descriptive and is used to describe staff making notes throughout the events
Acknowledgement of hard working staff	This code is used to describe the comments from Research Net that they saw and acknowledged how hard the staff work on the unit
Beginning of Co-Design	This code is used to describe the observations of the researcher that co-design was beginning at the event
Distracted	This code is used to describe the observations that people, both staff and Research Net were not paying attention to what was going on at the event
Staff feeling valued	This code is used to describe the researchers reflections that the staff were welcoming the validation they received from Research Net
Staff looking for improvement	This code is used to describe the positive feeling from staff that EBCD was going to make a difference

Code	Description
Understanding of EBCD	This code is used to describe an enhanced positive feeling from the member of Research Net carrying out the EBCD process and specifically relates to the members of Research Net who were patients on the unit
Unsure of EBCD	This code is used to describe the positive feeling that Research Net had during the staff event that they ran
Co-Design	This code is used to describe observation that staff didn't seem aware of what EBCD was
Power issues	This code is used to describe a specific observation that the researcher felt staff/Research Net were affected by the presence of a senior member of staff (director or consultant psychiatrist)
Hopeful of positive outcome	This code is used to describe feeling from staff and Research Net that ward would be improved

Appendix 16

Examples of Coding following interviews

Code	Description
Anxiety	This code relates specifically to anxiety surrounding interaction between staff and patients during the EBCD process; pre, during & post
Discovering	This code is specifically used to describe the actual process of Research Net undertaking the ethnographic observation of the ward
Factual	This is a code that reflects the description of the actual EBCD process that is described in the King's Fund EBCD toolkit
Things need changing	This code highlights standards of care on the unit that Research Net felt needed improving
Stressful	This code relates to the negative feeling of the person from Research Net carrying out the EBCD process
Emotionally uncomfortable	This code is specific to the description of Research Net members carrying out the EBCD process with staff
Interview process	This code is specifically used to describe the actual process of undertaking interviews, for Research Net
Improving care	This code is used to describe positive experience that Research Net found in their optimistic description of how they felt EBCD could make a difference
Uncertainty	This code is used to describe the uncertainty that was picked up from Research Net about whether they thought that EBCD would actually make a difference in improving care on the unit
Staff & patient relationships	This code is used to describe the observations of Research Net on the interactions between staff and patients on the unit
Staff differences	This code is used to describe the observations of Research Net on the differences in the way different members of staff interact with patients on the unit
Questioning care delivery	This code is used to describe the uncertainty that members of Research Net felt when they observed what they viewed as poor care being given to patients
Confidence	This code is used to describe the positive feeling of the person from Research Net carrying out the EBCD process
Pride	This code is used to describe an enhanced

Code	Description
	positive feeling from the member of Research net carrying out the EBCD process and specifically relates to the members of Research Net who were patients on the unit
Positive Feeling	This code is used to describe the positive feeling that Research Net had during the staff event that they ran
Concern for patient	This code is used to describe concerns that Research Net highlighted for patient care whilst they were observing the unit
Concern for staff	This code is used to describe concerns that Research Net highlighted for staff well being on ward, whilst they were observing the unit
Memories	This code is used to describe memories that the EBCD process triggered in members of Research Net in carrying out the EBCD process
Bad memories	This code is used to describe unpleasant memories that the EBCD process triggered in members of Research Net in carrying out the EBCD process
Cathartic Process	This code is used to describe the positive feeling that individual members of Research Net experienced whilst undertaking the EBCD process that helped them with their past experience when they were on a psychiatric ward
Understanding staff's perspective	This code describes Research Net's acknowledgement of the issues and difficulties for staff working on the unit
Collaboration	This code is used to describe reflections by Research Net on how staff and patients working together in the EBCD project
Working together	This code is used to describe reflections by Research Net on how they felt they (Research Net) worked together as a team.
Enthusiastic	This code is used to describe the positive feeling of enthusiasm that Research Net about undertaking the EBCD project
Breaking down barriers	This code is used to describe observations that Research Net made about it felt to them that traditional 'them and us' staff and patient barriers began to be broken down during the EBCD process
Honesty	This code is used to describe how they felt staff were honest during the interviews in the EBCD process
Being Blamed	This code is used to describe the perception that Research Net had that staff would not be honest with them during the interview part of the EBCD process
Staff anxiety	This code is used to describe how Research

Code	Description
	Net felt the staff would feel about participating in the EBCD process and being interviewed and observed by Research Net
Nervousness	This code is used to describe feeling that Research Net had prior to both the staff event and the joint event
Lack of Staff Defensiveness	This code is used to describe how Research Net felt the staff appropriately & effectively engaged in the staff event & joint event
Planning	This code is used to describe how Research Net organised and planned the staff & joint event
Patient empowerment	This code is used to describe how the running and chairing a table during both the staff event and joint event empowered the members of Research Net who ran the events
Reassurance	This code is used to describe the reassurance that Research Net felt in carrying out the staff & joint event following their planning of how the event should run
Patient in charge	This code is used to describe the feeling that Research Net had from chairing the tables at the staff & joint event
Patient leading research	This code is used specifically to describe how Research Net felt about they were leading the research during the EBCD process
Improving self esteem	This code is used to describe how the staff members of Research Net felt the experience of EBCD impacted on the patient members of Research Net
Time issues	This code is used to describe how Research Net felt about how much time is needed to carry out the EBCD project
Project Management	This code is used to describe the skill set that Research Net felt was needed to carry out the EBCD project

Appendix 17

Example of initial codes

1. Awareness of EBCD
2. Collaboration with patients
3. Collaboration with staff
4. Expectations
5. Anxieties
6. Concerns
7. Positive use of Research Net
8. Negative use of Research Net
9. Successful EBCD implementation
10. Unsuccessful EBCD implementation

Appendix 18

Example of Potential Themes

Theme	Description
EBCD awareness	This theme and its sub themes emerged from responses to the interview questions to the staff and members of Research Net about their experience of being involved in the EBCD intervention. The theme of EBCD awareness included sub themes of understanding, lack of understanding of EBCD process and also included scepticism of EBCD
Improvements to care	This theme and its sub themes emerged during explorations during interviews with both staff and members of Research Net, and their expectations of what would happen as a result of the EBCD intervention. These expectations were both optimistic and pessimistic
Emotional response to process	This theme was raised the most during the interviews and was the emotional responses from staff and Research Net to being involved in the EBCD process; sub-themes included anxieties, concerns and positive impact. There was a marked difference in emotional responses from members of Research Net and the members of staff.
Staff/patient collaboration	This theme was staff patient collaboration, how the staff and members of Research Net did or did not work together and what their experience of tis was; this theme included sub themes of collaboration with patients/staff, positive impact of patient/staff collaboration, working as a team, breaking down barriers, hope for positive impact, negative impact of patient/staff collaboration and concerns re collaboration. There was a difference in how members of Research Net and the staff expressed the theme of staff patient collaboration. Members of Research Net were overwhelmingly positive whilst the staff expressed concerns.
Power imbalance	This theme arose through the interview responses from both staff and Research Net and was an imbalance that was perceived by the participants throughout the EBCD process; there were sub themes of senior managers and staff, staff and patients, and patients and staff. There was a difference between the members of staff perceptions of power imbalances and the members of Research Net's perception. Staff felt power had shifted from them.

